



## On Being Ill (in Britain and the US): Illness Narratives of the Self

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### ABSTRACT IN ENGLISH

Illness narratives, pathographies and auto-pathographies, have been published in recent years in great number and so have critical studies on the cultural and social constructions of illness and on the impact such texts have on the writer and the reader. Yet few studies have analysed cultural differences between American and British illness narratives and addressed the issue of the different tradition of confessional writing in America and in Britain. In my paper I want to explore potential cultural differences between selected British and American illness narratives and focus on the specific ways in which the suffering self is constructed: How do the sick autobiographers theorize the act of writing about their illness? How do they represent themselves as authors and patients? How are the deteriorating body and impending death represented in these texts? My discussion of the suffering self will rely on Emmanuel Levinas and his concept of self and other that has influenced theories of affect studies, a field that also addresses notions of self and otherness. As the three British and also the three American autobiographers have all been acknowledged writers before the publication of their illness narratives, the aesthetic impact of these literary texts must be discussed as well since these narratives go beyond the personal experience of an illness.

### ABSTRACT IN GERMAN

In den letzten Jahren wurden zahlreiche autobiografische Krankheitserzählungen publiziert und kulturgeschichtliche und literaturwissenschaftliche Studien untersuchten kulturelle und soziale Krankheitskonstruktionen. In meinem Beitrag gehe ich den unterschiedlichen kulturellen Eigenschaften ausgewählter englischer und amerikanischer Krankheitserzählungen nach und konzentriere mich dabei auf Konstruktionen des scheidenden Subjekts: Welche Art von Selbstpräsentation wählen die erkrankten Autoren und Auto-

rinnen? Inwiefern theoretisieren sie ihren Schreibprozess? Wie sind kranker Körper und Tod in ihren Texten eingeschrieben? Bei meinen Ausführungen zum leidenden Subjekt beziehe ich mich vor allem auf Emmanuel Levinas und sein Konzept des Selbst und Anderen, wobei auch Einsichten aus den Affekttheorien berücksichtigt werden. Da fast alle der drei britischen und der drei amerikanischen Autoren schon vor ihrer Erkrankung publiziert hatten und anerkannte Schriftsteller und Schriftstellerinnen waren, muss auch der ästhetischen Dimension ihrer Texte nachgegangen werden, denn die literarische Auseinandersetzung mit ihrer Krankheit geht über die persönliche und individuelle Erfahrung hinaus.

**Keywords:** Illness narrative/autopathography, American/British autobiography, cultural difference, literature and medicine, ethics, affect studies, self/other, body, death, cancer, AIDS, chronic illness

In her canonical essay “On Being Ill” Virginia Woolf considers illness to be one of the experiences that affect our lives the most, and she even wonders why “illness has not taken its place with love and battle and jealousy among the prime themes of literature” (Woolf 2002, pp. 3-4). Although Woolf illuminates lucidly how the experience of illness disrupts people’s lives in most decisive ways, she does not mention any specific English characteristics regarding how (English) people cope with illness. In the wake of the Foucauldian “care of the self”, which always involves the self as much as sets of practices,<sup>1</sup> cultural critics have investigated how our thinking, feeling, and behaving is always embedded in our specific social and cultural practices. Foucault’s notion of “the care of the self” is not only based on those practices that influence the self and transform it (the power of knowledge), but also on those that effect a more self-guided transformation of the self, “by which one takes responsibility for oneself and by which one changes, purifies, transforms, and transfigures oneself” (Foucault 2005, p. 11). Arthur W. Frank uses Foucault’s concept and reconceptualizes it to illuminate the power and effect illness narratives produce and how they can be considered to take care of oneself because the act of narrating one’s illness is empowering, both for the writer and the reader. Telling a story is thus conceived of as a technology that influences and shapes not only the narrating self in a liberating way, but also the reader’s self that is involved in a dialogic relationship and is bound to respond to the suffering (other) self (Frank, 1998, p. 345). Yet, Frank does not address any questions about specific cultural and national influ-

<sup>1</sup> See Foucault’s “The Cultivation of the Self” and “Self and Others” in *The Care of the Self in The History of Sexuality*: 3. 2006, pp. 37–104.

ences; on the contrary, his approach to illness narratives focuses on the narrative act of the ill person to take care of the self.

Medical anthropology has demonstrated vividly that narrative is a primary means to connect the personal with the cultural. More recently interdisciplinary research has begun to explore specific national cultural histories of, for example, American psychotherapy,<sup>2</sup> but there is no such cultural and national history of illness to date. Max Saunders' recent illuminating study on *Self Impression: Life-Writing, Autobiografiction, and the Forms of Modern Literature* (2010) provides an overview of a whole range of British and American life-writing texts, but its focus is mainly on the relationship between fiction and autobiography, and not on national characteristics. Having explored numerous illness narratives of the past twenty years, most of which were written by American authors, I have recently been paying attention to potential cultural differences when reading such narratives by British writers. It has generally become acknowledged that each illness narrative constructs its own individual explanation of illness combined with biomedical explanations and that these constructions are also influenced by cultural and national contexts (cf. Epstein 1994, p. 4). A recent cross-cultural analysis of narrative accounts of cosmetic surgery decisions by British and American women shows that British women less often named vanity as a reason for surgery and American women emphasised more the "financial sacrifice and physical effort" (Gimlin 2007, p. 55) than British women. As Cheryl Mattingly and Linda Garro emphasise in the introductory chapter to their book *Narrative and the Cultural Construction of Illness and Healing*, "narrative becomes a vehicle for the problematic issue of representing experiences and events as seen from the perspective of particular actors and as elements of a cultural account that can tell us something about a social world, however local that world" (Mattingly and Garro 2000, p. 24).

Confessional writing and self-cultivation have a long tradition in American autobiographical writing, and what Diedrich calls "Oprafication" (Diedrich 2007, p. 63) is definitely an influence that needs to be paid heed to. By Oprafication she means the American fixation on self-improvement that borders on selfishness and may even exclude the other(s) because it stages self-improvement with an almost religious zeal. In autobiography studies a certain tendency towards a cultivation of the self in many American autobiographies has been observed<sup>3</sup> and it has been related to the specific historical and social conditions of the Ameri-

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<sup>2</sup> See for example the three books that are reviewed by Fred Pfeil in the *American Quarterly* 50.3 (1998): 652–61 in a short essay suitably entitled "One Nation in Therapy."

<sup>3</sup> See for example Timothy Dow Adams, *Telling Lies in Modern American Autobiography*.

can ideal of democratic self-realization as has been demonstrated by the exemplary “from rags to riches tale” of the role model Benjamin Franklin. Furthermore, the American history of self-invention and independence (from England) has furthered this legitimizing claim to the representation of an individual self. Similarly, the emancipatory strategies of African and Native Americans’ autobiographies also contributed to a specific American autobiographical tradition, often claiming the right to an independent and autonomous self.<sup>4</sup>

This tendency to act for oneself, to fight against all the odds of life and, if possible, to become a survivor (of, for example, an illness) has become less dominant in recent American illness narratives, as Frank points out (Frank 1995); this kind of “heroisation” is gradually being replaced by a less moralistic and less fighting position. Frank considers the so-called “restitution narrative” as one “display[ing] a heroism in the face of bodily breakdown” (Frank 1995, p. 93). Diedrich, joining the debate on this change of heroisation (Diedrich 2007, p. 55), still notices a tendency in American illness narratives to accept the challenge of (an) illness, whereas she contrasts this fighting self with the ironic self in a British illness narrative. Besides this tendency to create some ironic distance to one’s overwhelming suffering, Diedrich refers to a “culture of loss”<sup>5</sup> that characterizes British experiences because of the specific history (e.g. loss of empire), whereas the US has been able to distance itself from loss (e.g. of World War I and II). Like Diedrich (cf. Diedrich 2007, p. 68) I must admit that we literary scholars often base our findings on a limited selection of texts and in no way can we speak of a typology of national illness narratives. Nevertheless, I hope to elucidate a few differences in my discussion of selected British and American illness narratives.

Apart from the yearning for self-presentation, the role of “intimate publics” as theorized by Lauren Berlant in *The Female Complaint: The Unfinished Business of Sentimentality in American Culture* also plays a role, since we may argue that illness narratives express “particular core interests and desires” (Berlant 2008, p. 5) that then might be attractive to an intimate public of a specific illness (narrative). Although Berlant’s concept of “intimate publics” mainly focuses on texts belonging to so-called popular culture and illustrates how it is predominantly women (readers and viewers) who represent this “intimate public”, it also focuses on national and cultural identity as constructed in texts. Berlant sees an intimate public operate

<sup>4</sup> It must be emphasised, though, that many autobiographies by women and also by African and Native Americans construct a self that challenges this notion of autonomous self. See for example, Smith and Watson’s *Women, Autobiography, Theory: A Reader*.

<sup>5</sup> Diedrich refers to Andrew Sullivan’s *New York Times Magazine* article “There Will Always Be an England” (21 February, 1999: 38–45; 54; 70–73; 78–79; qdt.) in Diedrich (2007, pp. 67–68).

when its participants experience some kind of “subjective likeness” and participate in “varieties of suffering and fantasies of transcendence” (Berlant 2008, p. 5). The illness narratives to be discussed equally address very personal and intimate issues that are often rendered in a “complaining” voice to be understood by others who might be equally affected. Berlant’s “female complaint” exclusively focuses on women’s spheres and their (intimate) suffering, yet the reader’s affective participation in an illness narrative also includes suffering to a certain extent.

The focus on the patient’s suffering in illness narratives in the recent past has triggered criticism by some social scientists who argue that the “over-personalised” narrative has become the ultimate legitimisation of individual experience [e.g. Catherine Kohler Riessman (2003) and Paul Atkinson (2009)]. This critique might be less relevant in literary studies because literary critics do not conduct qualitative research with interviews as social scientists do and therefore for them “a more formal, sociologically-informed mode of analysis” (Atkinson 2009, p. 10) is not required. Instead, scholars of literature and culture studies focus on issues of representativeness in narratives that go beyond the depiction of personal experience, and such narratives contain imaginary realms which hint at a potential of humankind that can only be expressed through art. The aesthetics of literary texts can express matters that are otherwise hidden from us, but nevertheless reveal insights into human experiences such as illness. Therefore the illness narratives selected for my analysis are all written by authors who have been acknowledged writers before they decided to write about their illness.<sup>6</sup>

Comparing the six illness narratives, three British and three American ones, the following three main issues will be discussed: What constituted the impetus to write about illness? How do autobiographers present themselves as authors and patients? What kinds of representations of the body and of death are most conspicuously found in those narratives? The key issue underlying these questions is the positioning of the writing subject: How does the writing subject position him/herself vis-à-vis their readership? My discussion of these specific constructions of identities will be guided by the ethics of Emmanuel Levinas. In the relatively new field of affect studies and with the “affective turn” (Ticineto Clough and Halley 2007) within cultural studies and autobiography studies and its focus on subject identity and trauma, Levinas has become an authority regarding an ethical response to suffering. This response is intricately intertwined with the relationship between self and other; it is the other that is bound to respond to the other’s suffering: “Ethics is the location of a point of

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<sup>6</sup> The only exception is Ruth Picardie, who was a journalist and did not write any novels.

otherness” (Critchley and Bernasconi 2002, p. 15); similarly, affect “is in many ways synonymous with *force* or *force of encounter*” and is “born in *in-between-ness* and resides as accumulative *beside-ness*” (Gregg and Seigworth, 2010, p. 2). Reading a text by a suffering person about his/her suffering may equally trigger such a response because through the text we are engaged with “otherness”. The notion of affect lends itself well to a reading of illness narratives because we are dealing with bodily suffering and we as readers are affected in this exchange with an other.

Illness narratives with their rendering of suffering, are bound to affect us as readers in a variety of forms. For Levinas identity is always engagement with otherness: “The strangeness of the Other, his irreducibility to the I, to my thoughts [...] is precisely accomplished as a calling into question of my spontaneity, as ethics” (Levinas 1969, p. 43). Alterity and language are intricately intertwined because “language is already an address to and from the other” (Wyschogrod 2002, p. 191); we could even state that only through language does the other come into being. Although Levinas’s philosophical explanations and definitions of self, other, ethical, and ethics are not without contradictions and restrictions (cf. Bernasconi 2002, p. 234), his definition of identity and the consequential ethical response are useful for our discussion of Gillian Rose’s illness narrative. Levinas always includes the other when aiming at defining the self, and Rose’s text demonstrates that there is an unavoidable encounter between self and other. Yet one must emphasize that Levinas’s ethics does not provide any norms of action nor can it be related to a moral responsibility as may be expected in a clinical or therapeutic context (cf. Perpich 2–16). Similarly, Trisha Greenhalgh, who also raises ethical issues in her approach to illness narratives, claims that reading narratives make us respond to very specific situations and positions, and they do not necessarily call for (moral) action (Greenhalgh 2006, pp. 91–93).

Representations of the (sick) body are intricately intertwined with the issue of identity constructions, thus descriptions of bodily processes and deteriorations of the body need scrutinising as they tend to take more space in illness narratives the more serious the state of the autobiographers’ illness becomes. In my work I have noticed that the more serious the bodily deterioration is the more prominently bodily sensations and experiences figure, and the self seems to be constructed entirely through the body, or, as Thomas Couser puts it, “pure illness narrative tends to disengage the body from the self in the way that medical discourse often tends to do” (Couser 1997, p. 14). Rita Charon, the founder of “narrative medicine”, speaks of “the novelization of the body” in order to express the crucial role of (our) bodies in medicine and story telling: It “is the exposure of the body’s plot, form, and voice, temporality, and governing

images” (Charon 2011, p. 47). According to Charon “narrative medicine” not only aims at improving narrative competence of medical professionals, it also expresses the power of illness narratives to move us, to *affect* us. The turn to affect then is also a turn away from the mind and toward the body, a turn away from the paradigm of representation.

Writing about one’s own death equally falls out of the paradigm of representation because it always implies writing about what cannot be known. And yet, not only in texts dealing with a life-threatening illness, but also in almost all illness narratives, death is omnipresent. My analysis aims at providing insight into the ways in which death is inscribed in those texts and in what ways these inscriptions influence notions of the self and its relation to the other(s).

Amongst the three texts representing each culture, two texts are by women writers and one by a male author: Among the British ones are Gillian Rose, *Love’s Work* (1995), Ruth Picardie, *Before I Say Good-Bye* (1998), and Tim Parks, *Teach Us to Be Still* (2010). The American writers include Harold Brodkey, *This Wild Darkness* (1996), Marilyn French, *A Season in Hell* (1998), and Siri Hustvedt, *The Shaking Woman* (2010). Three of the autobiographers suffer from and die of cancer (Gillian Rose, Ruth Picardie, and Marilyn French), whereas one dies of AIDS-related symptoms (Harold Brodkey); the other two texts describe chronic illnesses whose origin remains unknown (Tim Parks suffers from chronic pain in the abdomen and Siri Hustvedt from bouts of shaking when under stress of speaking before an audience).

## WRITING ABOUT ILLNESS, ME, AND THE OTHER

All six autobiographers explain why they decided to write about their experience of illness, yet their narrative strategies differ greatly. Gillian Rose, a British philosopher and professor of social and political thought at the University of Warwick, wrote a philosophical memoir as she was dying of cancer in 1995. Her illness narrative *Love’s Work* only becomes an illness narrative in the second half of the book (thus far she does not mention her illness at all) and then she explicitly explains that writing about her illness means to “die forward into the intensified agon of living” (p. 71), thus expressing the intensity and urgency of life writing. Rose addresses the reader in a pleading/imploping way (p. 72) and she admits being concerned about people’s difficulty in dealing with her “renewed vitality” (p. 72). Writing about her illness obviously endows her text with a vitality and intensity that may disconcert readers. Rose is aware of the special “quality” inherent in her text and addresses the reader directly as “the other”

who should keep on listening in the face of suffering (cf. Lyotard 1988, *The Differend* p. 13; cf. also Diedrich 2007, p. 148). By directly addressing the reader as “you” the author invites the reader to engage in an explicit dialogue. More than once she addresses the reader in a pleading way and asks him or her to engage in what might become a difficult undertaking. This explicit positioning of the reader vis-à-vis herself is a narrative strategy other autobiographers writing about their illness employ as well:

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Dare I continue? Are you willing to suspend your prejudices and judgment? Are you willing to confront and essay a vitality that overflows the bumble mix of average well-being and ill-being – colds and coughs and flu, periodic lapses in the collaboration with culture, or headachy days ...? (Rose 1995, p. 72)

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Rose, the patient and writer, is aware of the potential difficulties a reader might envisage when engaging in a dialogue with her and even names risks and uncertainties for both sides. The fragile, yet touching encounter between self and other is verbalised and theorised here by the sick self that mirrors the complex bond between writer and reader.

For Ruth Picardie (2000), writing openly and publicly about her illness in a weekly column of the *Observer* is quite evidently linked to her profession as a journalist and therefore she does not hesitate to describe her ordeal in a very direct and detached manner. She intends to describe the implications of the “C-word” precisely and shamelessly, not without using black humor extensively. Her sense of humor enables her to name the cruel fact that she has only a few more months to live and to describe the atrocities of chemotherapy instead of being “all American” (p. 20) and “without objective assessment” (p. 19) like Kathy Acker, who obviously did not want to face the harsh realities of her illness.<sup>7</sup> A striking example of her typically British black humor is the following passage: after learning about her diagnosis she writes in an email to her friend: “But this is the fat, stained, piggy-eyed parallel world of illness, and your lump, I’m sorry to say, is actually cancer. [...] As you’d expect, the diagnosis turns you into a grumpy, bitter envious old cow” (p. 44). French’s reaction to her diagnosis, for example, is phrased quite differently: “I was silently terrified, unable to explain the malaise that permeated my being” (French 1998, p. 13). She is eager to emphasize that she felt unable to write at certain stages of her treatment, and most of her memoir seems to have been written retrospectively; indeed, she even “asks the reader’s indulgence for [her] long recital of personal ills” (p. 243), which, she adds, she mainly wrote in order to

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<sup>7</sup> Kathy Acker, after having undergone mastectomy, stated publicly she was cured, although there were obvious signs that the cancer had spread to her lymph nodes.

cope with her traumatic experience. But in spite of this urge to express her suffering in words ["I could tell it (the whole story) over and over without tiring of it" (p. 243)], French also explicitly addresses the reader(s) hoping that "others might find it helpful" (p. 243).

Tim Parks, an accomplished and well-known British novelist, ponders why he yearns to convey his experience to readers: he could not imagine writing about such private matters as the body (Parks 2010, cf. 1), and yet, as he discovered that a breathing exercise to "sit still" (1), i.e. to meditate and listen to his body (instead of medication), opened up new facets of his life, he decided to write about it because it "had become too inviting a conundrum to be left unwritten" (2). Writing about his illness must not be "a complaint" (p. 207), but instead is aimed at providing insight and elucidation. Parks, who has been living in Italy for more than twenty years, is aware of his own background with middle-class evangelical Anglican parents for whom the "body was a necessary hassle on the way to success and paradise" (2) and therefore he is bound to write against the silencing of the body. Unlike Rose Parks he is less concerned about his readers' responses, although he, too, opens himself up to the reader by writing so openly about his pelvic pain and describing minutely the procedure of a cystoscopy. Writing so frankly about a taboo topic is bound to trigger a response from the reader, even if he/she is not explicitly addressed. Inserting a photograph of such a cystoscopy foregrounds Parks' vulnerability and exposedness, which, in turn, speak directly to the reader's affect.

At the beginning of his AIDS memoir Harold Brodkey theorizes writing about private matters: He wants to leave his own *testimony* (emphasis mine) behind, and, as is the case with other AIDS memoirs, he is convinced of "the *important* validity of [his] ideas" (Brodkey 1996, p. 14; emphasis his) in his text, thus implying the necessity of writing AIDS into his text. In this respect Brodkey writes in the tradition of the AIDS memoir, engaging in an activist manner to fight against the silences and taboos confronting people with AIDS. And yet shame is a topic that emerges again and again and is related to a troubled childhood. By writing openly about AIDS, Brodkey is able to face his traumatic childhood (he was sexually abused by his adoptive father), yet he still feels guilty and ashamed.

In the course of his probing narrative a number of selves becomes manifest: at times Brodkey describes himself as a man whose "life has changed into death, irreversibly" (p. 17) and writing about it continuously creates "this identity, this mind, this particular cast of speech" (p. 169). Being ill makes him create "imaginary faces" because "[o]ne has a sense specialized by illness" (p. 139), therefore he does not believe that terminally sick people can actually describe other people accurately as

they belong, like himself, already to the dead. This imminence of death endows Brodkey's speech with an urgency, but also with a serenity that he calls "happy": "it seems very strange to think one could enjoy one's death" (p. 176). On the other hand, there is a desperate self without hope and disillusioned by the suffering. And yet this self is convinced to convey to the reader unique and truthful insights and therefore is much more prominent than the wavering, doubting self. The "candor about AIDS" (p. 154) is not only addressed to a specific reader that might be supportive of people with AIDS, but also to a public audience that learns about most intimate moments of one who is about to die. Einat Avrahami has commented on Brodkey's ambivalent confessional mode in more detail, explaining how Brodkey "resolv[es] the tension between his desire to normalize the experience of dying and his awareness that dying from AIDS is always already constrained by the particularly oppressive cultural metaphors of AIDS" (Avrahami 2003, p. 167). Birkner in her work on AIDS narratives speaks of a kind of viral narrative mode (cf. Birkner 2006, p. 300) to describe the desperate search for a meaningful representation of the dominating yet destructive virus. For Birkner viral narration illustrates the fact that the virus itself is at the center of those texts and prevents the autobiographer's attempt from constructing a narrative subject without the virus.

Marilyn French's *A Season of Hell* indeed depicts a painful journey from the moment of learning of her diagnosis of esophageal cancer through chemo sessions to the time of healing and partial recovery while always being supported by her family and community. French comments on the act of remembering, explaining that only by writing down what happened to her was she able "to deal with her memories" (French 1998, p. 244). Yet she does not elaborate on this necessary act of writing any further; instead she simply states that it was possible "by what magical means I don't know" (p. 244). Similar to Brodkey, she also writes about illness and happiness: As she puts it, she is "happy that sickness, if it had to happen, brought [her] to where [she is] now. It is a better place than [she has] been before" (p. 256). Only through this experience of illness did she gain insights into (her) life; having been on the brink to death, she now realizes that certain ideals in (her) life cannot be fulfilled.

Writing about her illness, whose origin neither Siri Hustvedt nor her doctors know, seems to be a natural response for a writer who has an inclination for the history of medicine. Furthermore, having been involved in teaching a writing class to patients of a psychiatric clinic for some time, writing about her illness is the most natural way of exploring it and trying to understand its complexity: "What began with curiosity about the mystery of my own nervous system had developed into an overriding passion" (Hustvedt

2010, p. 6). This passion makes her document all of her attempts to explain the reasons for her shaking. Describing her sensations and feelings openly does not seem to bother her at all. Her specific disposition of “translat[ing] everything into bodily feelings and sensations” (p. 117) obviously makes her experience extreme empathy with other human beings and she reacts very strongly towards visual impressions. Yet, in spite of exact descriptions of her emotions and thoughts, self-presentation does not become a narcissistic self-performance; instead, Hustvedt remains detached and critically analyses her troubled state. Her investigation of the possible origin of her illness makes her embark on a journey through the medical history of the psyche from Galen via Charcot and Freud to neuroscientists like Antonio Damasio. Yet the origin(s) of her shaking fits cannot be unravelled. She herself provides an answer at the very end of her inquiry: “I am the shaking woman” (p. 199), and it is the narrating act enabling her to come to this conclusion. Hustvedt not only performs this “ongoing narrative,” she also implicitly critiques scientific discourse by using her narrative as the only possible way to integrate her illness and to become the shaking woman. In the interview she utters this critique more radically:

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Science operates from a third person perspective, which is of tremendous value. But at the same time, there is no such thing as perceptual neutrality – when scientists interpret results, they are bringing their subjective selves to the experiment. I think this should be recognised. It is easy to forget that in some important philosophical way, there is no third person.<sup>8</sup>

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Besides providing a short history on the traditional mind-body dichotomy and contesting binary theories, Hustvedt’s narrative dwells on the relationship between “I” and “you” that governs language (cf. Hustvedt 2010, p. 55). In this respect her illness narrative not only demonstrates this ethical imperative between self and other; in it she also theorizes language and identity. Again, she comments on recent insights from the field of neuroscience and on the infant’s brain development and the infant’s capability to differentiate between self and (m)other. And yet, she implicitly contradicts the neuroscientific claim of a prelinguistic autobiographical self as suggested by Damasio (1999) and Eakin (2008) by constructing a searching and sceptical self.

All six autopathographers comment on the fact that they are telling us about their illness, and it is difficult to identify differences between the British and the American texts. Yet, upon further inspection one notices

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<sup>8</sup> Interview with Siri Hustvedt by Celeste Biever, biomedical news editor from *CultureLab* (3 Feb 2010). <http://www.newscientist.com/blogs/culturelab/2010/02/memoir-of-a-puzzling-mind.html>.

that the British writers self-critically reflect on their own life writing in a slightly different way than their American counterparts. Rose, Picardie, and also Parks do not question the autobiographical act as such, yet they all seem to be self-conscious about it nevertheless, and are aware of the cult of selfhood. At the same time, Rose and Parks emphasize that writing about it is the only way to cope with their ordeal. Among the three American autobiographers, Brodkey is the only one who more explicitly raises the issue of writing about illness because he considers the act of writing about AIDS as a political act [“I’d rather be open about AIDS and scoff at public humiliation than feel the real humiliations of lying” (Brodkey 1996, p. 115)]. French and Hustvedt present their writing about illness as a “natural” way of coping, since writing has always been their occupation. Thus we do not find explicit discussion about their own writing, nor are we addressed explicitly as readers. Yet Hustvedt is aware of the performative power of her narrative because she becomes “the shaking woman” in the course of her narrative; narrating her illness. “[s]he has become part of [her] story” (Biever 2010). Hustvedt engages much less with the reader than with her own self/selves, and a Levinasian ethical engagement between self and other is less tangible.

### THE STORY OF ONE’S BODY

Comparing the two sets of autobiographers with regard to representations of the body one notices that the British examples develop a discourse of the body that is astonishingly direct, blunt, and honest, whereas their American counterparts seem to be less explicit regarding bodily processes. Rose is the most innovative writer in this respect; she actually wants to invent a new genre for her illness narrative, a so-called “colostomy ethnography” (Rose 1995, p. 87): By combining medical phrases with philosophical enquiry she creates this “colostomy ethnography” and deliberately uses words and phrases like “I handle my shit” to demonstrate the concreteness of experience/materiality of illness and of language at the same time: “I no longer employ the word as an expletive, discharging intense, momentary irritation into its void of meaning” (p. 89). Her body has changed and is no longer describable as before; since her body has changed, her way of inscribing it into a text must also be invented. The experience of illness makes her invent this new genre and the reader/listener must respond to a hitherto unknown discourse.

For French, writing about her ordeal is a normal reaction as a feminist writer (the personal is the political). She minutely describes her changed body that “has been damaged by chemotherapy or radiation” (French 1998, p. 240). But there are no such explicit descriptions as in

Rose, Parks, or Picardie. Parks and Rose both write about body fluids and excrements, expressing what might otherwise be considered a taboo or might be threatening to face, thus giving voice to the abject and to the “horror” that such bodily wounds provoke. In this respect Julia Kristeva’s concept of the abject does not signify for the subject “the place where meaning collapses” (Kristeva 1982, p. 2); on the contrary, it is expressed in a new form and new meaning for the sick subject is created. Brodkey does not explicitly describe his bodily deterioration, although the body has always played a prominent role in his life. Now being terminally ill, he is more reticent about it: “I am only saying that I am prejudiced toward a nakedness in print – toward embodiment in black-and-white” (Brodkey 1996, p. 30). And yet, there is an increasing separation between body and mind because the weaker the body gets, the less it seems to be related to Brodkey’s mind: “my memories no longer apply to the body in which words are formed” (p. 173). As mentioned above, this separation between body and mind can also be observed in other illness narratives in which the deterioration of the body is acute. Hustvedt, who is not confronted with a life-threatening illness, is quite reticent about her body and focuses more on mentally and emotionally extraordinary and disquieting processes. When writing about the body she theorizes it and questions the dichotomy body-mind (cf. Hustvedt 2010, p. 69) by providing numerous references to different directions in the history of medicine.

Interestingly enough, we can state that the body is much more prominently present in the three British illness narratives and that very intimate and private features of the body are presented. Thus, the often assumed notion that Americans are less constrained and more willing to reveal intimate concerns does not pertain at all. The confessional and self-cultivating tendency often observed in American autobiographies does not necessarily mean descriptions of extreme bodily deterioration and suffering. Being ill and writing about this experience can trigger entirely different forms, and yet all of them call on us to care for the sick self.

### LIFE (BEYOND) WRITING: INSCRIBING DEATH

All six autobiographers write explicitly about death; Picardie and Brodkey deal most openly and directly with their own imminent death. For all of them death is not something entirely ungraspable – on the contrary, their illness makes them create a language that otherwise may not have been possible. Rose’s text, with its title *Love’s Work: A Reckoning With Life*, most impressively evokes an empowering force because in spite of her suffering from cancer her “life affair, [is] *love’s work*” (p. 99), whereas Brodkey’s text with its title *This Wild Darkness: The Story of My Death* conveys a much

more somber tone. In his introduction to the 2011 edition of Rose's book, Michael Wood writes about the lecture she delivered one year before her death on time and death and explains Rose's way of coping with her terminal illness: instead of being afraid of the dark moments, "[o]n inhabit hell, to keep one's mind there, is to find the hope that is not the opposite of devastation but its complement" (Wood 20 xiii).

None of the six narratives evades the confrontation with death, and it is most overwhelming to read Picardie's statements on her imminent death and on having to leave behind her husband and her two-year-old twin girls. Also Hustvedt, who is not faced with imminent death at all, speaks of "the reality of death" (Hustvedt 2010, p. 99) she is confronted with when reminiscing about her deceased father, and we should not forget that her illness struck her for the first time when she was about to deliver a speech at a memorial service for her father.

Writing about a serious illness always also means writing about death, and since death ultimately can only be written about in anticipation and always "*falls outside the thinkable*" (Certeau 2002, p. 190) it seems as if writing about illness brings us (both writer and reader) as close as possible to death. Rose's last sentence expresses the power of language, even in the presence of impending death she believes in "working in this sin of language and lips" (Rose 1995, p. 135); it is probably not coincidental that "lips" is the last word because it is through the lips that we exhale our last breath. As Levinas also maintains, the recognition of the other is most essentially manifest in suffering and death. The naked and cold body represents most intensively the exposedness and vulnerability of the other (cf. Levinas 1969, p. 75). What is at stake, though, is the fact that the reader is always implicated and if the patient/narrator is not to live on, we (and/or the person present at the moment of death) are the ones to either imagine or utter the sentence "*you died*" (Belling 2004, p. 154), and "the one is called upon to respond to the vulnerability, destitution and nakedness of the other" (Shildrick 2002, p. 88).

Writing about the experience of illness, British and American writers proceed differently when theorizing on writing about it and when inscribing the body into their text, and from our analysis one may conclude that the American tradition of personalizing and individualizing makes our autobiographers less hesitant to write about their illness than the British ones, who, nevertheless, emphasize bodily processes. The American tradition of self-cultivation and "Oprafication" mentioned at the beginning cannot be related to Brodkey, French, and Hustvedt since all three tend to be much less open and explicit when describing their bodily suffering. It seems as if the three writers, who had all written novels before, are critical of the American tradition of autobiographical confessional writing with

its goal for self-improvement. Furthermore, the fact that they write about illness and its disruptive effects may have prevented them from envisaging any self-realizing dreams. And yet, the illness narratives by their British counterparts do not dwell on self-cultivation either; their focus on exact and sometimes even shameless descriptions of their suffering (bodies) tend to make the reader aware of the harsh everyday realities of a sick person and to engage in the autobiographer's attempt at understanding those realities. When it comes to death it is impossible to make out differences. Although all six writers thematize aspects of death differently, they all refer to death explicitly and openly and, if necessary, confront harsh reality (Rose, Brodkey, and Picardie). Knowing that nobody can know what it means to die, they only write about what they are feeling at the very moment, which is still very much related to life and their specific lives. Death indeed seems to "confer authority upon the narrative and the narrator" (Stacey 1997, p. 243).

In spite of their different narrative strategies aiming to engage their reader(s) in a dialogue, all six autobiographers tell a story whose power derives from the interface of a (suffering) body, voice (narrating), and self (constructed in the text) and whose effect is bound to affect us as readers. As an autobiographer/narrator/patient they all attempt to reach "the other" (the reader/s) by continuously constructing new forms of a language/discourse that serves to express their suffering and reach a reader/an audience. The encounter between the sick writing subject and the reader is not shaped by any conspicuous national or cultural narrative characteristics nor is a clearly discernible national or cultural discourse at work. All six illness narratives construct a private space into which we readers are invited and made to take "care of the self": Telling us what it means to be ill always means caring for each other.

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