

Rosalia Baena

## Recognition and Empathy in Illness and Disability Memoirs

### Christina Middlebrook's *Seeing the Crab* and Harriet McBryde Johnson's *Too Late to Die Young*<sup>1</sup>

Focusing on the concepts of narrative empathy and recognition, this article aims to explore ways in which personal narratives may promote a renewed perception of illness and disability. Taking its cue from studies by Rita Felski (2008) and Suzanne Keen (2013), it investigates how empathic experience reflects the force and intensity of aesthetic encounters. Specifically, it addresses two texts that deal with the experience of illness and disability: Christina Middlebrook's *Seeing the Crab. A Memoir of Dying Before I Do* (1996) and Harriet McBryde Johnson's *Too Late to Die Young. Nearly True Tales from a Life* (2005). These authors write their lives in order to influence the way we perceive and understand illness and disability. Their major cultural mediation lies in their willingness to connect with their readers both affectively and cognitively, counter-arguing the culture of denial of death and rejecting pity and compassion in the face of illness and disability.

### 1. Introduction

In her groundbreaking book *Uses of Literature* (2008), Rita Felski argues that we need to grasp the texture of everyday reading practices, commonly neglected in literary criticism (cf. 132). In this regard, we may further investigate the relations between individual acts of reading and their broader social contexts, and thus return to the recognition of literature as a form of personal and social knowledge. With the rise of cognitive literary studies, more critical attention is being paid to the empathic connection between author, text and reader.<sup>2</sup> Moreover, empathy is enhanced by witnessing another's emotional state, by hearing about another's condition, or even by reading; indeed, in the process of reading, empathy refers to the sharing of affect between story and reader. Specifically, the concept of "narrative empathy" – a term coined by Suzanne Keen to designate an affective element of the reading operations investigated by cognitive narratology – may serve as a useful critical tool in our examination of contemporary reading practices. As well as paying attention to readers' responses, Keen's theory of narrative empathy elaborates the uses to which authors put their human empathy in their stories. She thus defines narrative empathy as "the sharing of feeling and perspective-taking induced by reading, viewing, hearing, or imagining narratives of another's situation and condition" (Keen 2013, paragraph 1).

In this critical context, I will focus on personal narratives of illness and disability, a genre that has proliferated in the last few decades and that constitutes a useful example with which to explore contemporary reading practices (cf. Conway 2007, 140). These memoirs merit critical attention, especially as it was not until the late 20<sup>th</sup> century that illness and disability narratives were definitely established as a literary genre (cf. Jurecic 2012, 2). Illness is one of the most universalizing of experiences: as Kathlyn Conway (1996, 75) puts it, “[i]llness is the great leveler. Here sit men and women, young and old, rich and poor.” And it is the interest of contemporary readers in first-person accounts that explains the proliferation of writing and reading of illness memoirs. Here readers can connect with the everyday concerns of illness, vulnerability, and mortality (cf. Jurecic 2012, 94). These texts also relate to a generalized concern with medical, as opposed to social, paradigms of illness. Considered a reaction to a medical model “so dominated by a biophysical understanding of illness that its experiential aspects are virtually ignored” (Hawkings 1993, 11), illness narratives are valued for their affirmation of subjective human experience and human agency and for their challenge to dominant healthcare ideologies (cf. Sakalys 2000, 1469). Their model tends rather to consider illness as a social and cultural construct.

As Rebecca Garden (2010; 2015) explains, first person memoirs provide a critical resource by offering a means of examining the social contexts and determinants of illness and disability, as they aim to broaden the emotional and intellectual understanding of what being ill really entails. These are powerful texts that invite profound and intimate engagement with the author’s life, and by representing their own emotional as well as mental engagement with illness and disability, their writers lead us to appreciate how narrative empathy works in the reading process. They show how stories empower those who are ill or disabled, thus projecting the need for recognition and knowledge instead of the more common reactions of pity or even self-blame. Fear, anger, and sadness also play a part in illness, and these texts claim that emotional restraints should not be imposed on such feelings (cf. Baena 2016, 75). The memoir-form ultimately allows for these journeys to be examined, understood, and recognized (cf. Baena 2017, 178).

This article aims to analyze two memoirs dealing respectively with terminal illness and severe disability: Christina Middlebrook’s *Seeing the Crab. A Memoir of Dying Before I Do* (1996) and Harriet McBryde Johnson’s *Too Late to Die Young. Nearly True Tales from a Life* (2005). We will see how these two authors relate their lives in order to connect with their readers both affectively and cognitively and in doing so to influence the way we perceive and understand illness and disability. Their major cultural mediation lies in their willingness to counter-argue the culture of denial of death, as well as the rejection of pity and compassion in the face of illness and disability.

## 2. From Empathy to Recognition

It could be argued that one of the most common themes in both illness and disability memoirs is the need for recognition of difference. Here the connection between the concepts of narrative empathy and recognition may be useful. Interestingly, Lou Agosta (2014, 7) provides common ground for these two concepts, describing empathy as a process that consists not only of affective but also of a cognitive and interpretive receptivity, encompassing understanding and hence also recognition. Specifically, in this communication process, understanding is an important constituent relating empathy and recognition. Empathic understanding is a dimension in which the other is acknowledged in relatedness as a possibility of human flourishing: “a possibility of choosing autonomously, making commitments, and implementing them” (ibid., 4). The paradigm case for this empathic understanding is, then, recognition of the other: recognition – in the full meaning of that term – of what is possible for the other. As readers of illness and disability memoirs we may gain understanding of their authors’ life-experiences and with it the capacity to recognize their life experiences as valuable.

In investigating the role of affects in criticism, Rita Felski (2008) has used the term “recognition” as one of the main forms of engagement in the reading process. She proposes

that reading involves a logic of *recognition*; that aesthetic experience has analogies with *enchantment* in a supposedly disenchanted age; that literature creates distinctive configurations of social *knowledge*; that we may value the experience of being *shocked* by what we read (ibid., 14; emphasis in the original).

With these four modes, Felski highlights the need to acknowledge the common reader in literary analyses. She also deploys the concept of “deep intersubjectivity” (ibid., 91) to refer to the representation of persons as embedded and embodied agents. As these narratives unfold, we may see how recognition is about both self-perception as mediated by the other and the perception of otherness by the self. It can refer to acknowledgment, a claim for acceptance, dignity, and inclusion in public life: “Its force is ethical rather than epistemic, a call for justice” (ibid., 29f.). In the same sense Charles Taylor (1994), in his essay “The Politics of Recognition”, discusses to what extent “recognition forges identity”, and how this is invoked by minority groups:

Our identity is partly shaped by recognition or its absence, often by the misrecognition of others, and so a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or demeaning or contemptible picture of themselves. Non-recognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being. (Ibid., 25)

As we will see, illness and disability memoirs present many subtle ways of both non-recognition and misrecognition. The politics of recognition refers, therefore, not only to the public acknowledgment of someone’s existence, but also to the full affirmation of their being:

Reacting against a history of condescension and marginalization, [...] minorities seek to affirm their distinctiveness and to have it affirmed by others. To be recognized, in this sense, does not mean having one's differences noticed (for they were always noticed), but having those differences seem as desirable and worthy. (Felski 2008, 47)

Reading contemporary illness and disability memoirs, we are in a position to recognize agency and self-definition. As Hilde Lindemann Nelson (2001, 24) explains, "freedom of agency requires not only certain capacities, competencies, and intentions that lie within the individual, but also recognition on the part of others of who one is, morally speaking." In the next section I will turn to Middlebrook's and Johnson's texts as effective forms of agency both in their self-definition and in the recognition they elicit through their enhancement of narrative empathy.

### 3. Illness and Disability Memoirs

Christina Middlebrook's *Seeing the Crab* (1996) is an early example of cancer writing. Following the emblematic Audre Lorde's *The Cancer Journals*, published in 1980, there have been enough publications now to make the breast cancer narrative a subgenre of its own among illness memoirs. Born in 1941, Christina Middlebrook was diagnosed with breast cancer Stage IV, already with extended metastases when she was 50. She recounts in vivid detail how she then underwent a bone marrow transplant and months of highly aggressive treatment. Trained as a psychotherapist and Jungian analyst, Middlebrook uses her analytic skills to expose what she went through, her reactions, pains, and the lack of understanding on the part of family and friends, as well as health professionals. A confident writer, she departs from conventional formulas and, because her cancer was so advanced, skips over many of the obligatory scenes of earlier narratives. Thus in a single sentence she disposes of the initial discovery of a lump, diagnosis, surgery, and chemotherapy (cf. Middlebrook 1996, 32), beginning her narrative in detail only with the bone marrow transplant – a controversial last-ditch treatment (cf. Couser 1997, 73). Middlebrook recounts her journey toward both social and self-recognition as a quest that included accepting cancer as part of what she was and is. This process began early in her life with the disease: "In the beginning, reeling from the shock, when I felt drowned in information that threatened to swamp all of life as I had known it, even then I said I had to get to know this cancer, this vile crab, and make it part of who I am" (Middlebrook 1996, 4). She soon realized that repairing her damaged identity would require her to know more about cancer and about living with a chronic illness. In sharing this process, Middlebrook makes it possible for the reader to experience an empathic understanding that allows further recognition.

One of the best examples of the genre of writing concerned with the experience of severe disability is Harriet McBryde Johnson's *Too Late to Die Young*

(2005). Born in 1957, Johnson suffers from a severe congenital disability due to a neuromuscular disease that puts her in a wheelchair. She needs help for the basic chores of getting dressed, undressed, having a bath or even eating. However, contrary to what might be expected, Johnson is a successful lawyer in Charleston, South Carolina. She took a degree in history, a master's in public administration, and went to law school. Her personal account of activism and advocacy for disability rights – a commitment that helped promote the *Americans with Disabilities Act* in 1990 – is an excellent example of what G. Thomas Couser (2009) has called the “New Disability Memoir.” In her memoir, she describes her participation in various events of the movement, such as her public appearance in a protest to the visit of Ronald Reagan to her campus, the University of South Carolina, or her public debate in Princeton with Peter Singer, challenging his belief in infanticide and euthanasia for disabled children (cf. Johnson 2003: this chapter of her memoir was published in the *New York Times* and made her quite well known).

Both the content and form of Johnson's memoir already defy expectations: “my stories don't aim to satisfy the general curiosity about what it's like to live in a withered body like mine or feed the public appetite” (Johnson 2005, 4). Johnson explicitly scorns the usual generic formulas of disability memoirs:

The world wants our lives to fit into a few rigid narrative templates: how I conquered disability (and others can conquer their Bad Things!), how I adjusted to disability (and a positive attitude can move mountains!), how disability made me wise (you can only marvel and hope it never happens to you!) [...]. (Ibid., 2f.)

Instead, she displays a collection of what she calls “nearly true stories”, “as true as memory allows” (ibid., 4). Each chapter displays scenes and reflections from the particularities of her life, her encounters with many different people, and the flow of her narrative is driven by a simple desire to know “what-happens-next” (ibid.). Storytelling, for Johnson, is not only a natural way of communicating – as it is for any Southerner – but also “a survival tool, a means of getting people to do what I want” (ibid., 3). She recounts how she is used to telling stories as a way of payment to people for driving her around. This explains the conversational tone she uses, constantly permeated with an intelligent sense of humor and an ironical take on what happens to her. And although the different tales of *Too Late to Die Young* are organized in chronological order, they do not form a continuous, linear narrative: there is no overarching plot, and the episodes themselves are not even firmly plotted, defying the structural pattern of the more traditional disability memoir.

In her book, Johnson openly explains the devastating impact on her body of more than four decades of a muscle-wasting disease. At the time of writing, Johnson is in her mid-forties and extremely thin: “flesh mostly vanished, a jumble of bones in a floppy bag of skin” (ibid., 1). She also describes in detail the effects of her disease on her spinal cord, and other painful consequences. However, while she openly draws the readers' attention to the striking deformities in her body, she is also quite ready to change our perspective on it. Johnson describes, for example, that her body would naturally ask for a different shape:

When, in childhood, my muscles got too weak to hop up my spine, I tried a brace for a while, but fortunately a skittish anesthesiologist said no to fusion, plates, and pins – all the apparatus that might have kept me straight. At age fifteen, I threw away the back brace and let my spine reshape itself into a deep twisty S-curve. Now my right side is two deep canyons. To keep myself upright, I lean forward, rest my rib cage on my lap, plant my elbow on rolled towels beside my knees. Since my backbone found its natural shape, I've been entirely comfortable in my skin. (Ibid., 1f.)

What might be perceived as deformity that demands to be corrected is in fact the best option for her and the natural way for her to live. The reader is now ready to recognize that there is another way of looking at her deformity: her situation does not have to be perceived as a tragedy but as an example of being not dis- but differently abled – a formulation that is one of the major ideological achievements of the Disability Rights Movement. In a similar vein, Johnson challenges commonly perceived assumptions about beauty and quality of life. Regarding her physical appearance, she explains: “It’s not that I am ugly. It’s more that people don’t know how to look at me.” (Ibid., 1) She also recounts how she is perceived, in fact, as a rare kind of beauty. Besides, some people in Charleston call her “Good Luck Lady”: “they consider it propitious to cross my path when a hurricane is coming and to kiss my head on voting day.” (Ibid., 2) Overall, she is quite satisfied with her life. She describes in detail why generalized perceptions of it as tragic are not true: “My stories tell them that, yes, I’m a cripple in a dramatic state of decrepitude, but also, I have a life.” (Ibid., 192) As the reader gets to know more about this life in its everyday forms, the realization dawns that it is not very different from that of a non-disabled person. Harriet Johnson eventually died in 2008 at the age of 50 but, as she insists all through her autobiography, she led a remarkably good life. The empathy that arises through this first-person account of everyday feelings and actions is based on the immediate experience that Johnson communicates of that life:

I know I am as alive as any of them, and they are as mortal as I. I am set apart not by any basic realities, but by perceptions – theirs and mine [...]. I study, play, work, find a place in a family and a community, and enjoy the many delights that continue to fall on me. As my body continues to deteriorate, my life looks more and more normal [...] life is a great gift, worth hanging on to. (Ibid., 11f.)

#### **4. Not Denial but Recognition**

Nevertheless, as many illness and disability memoirs confirm, contemporary culture regularly fails to recognize either the differences in the life-experience of their authors or the values they represent. A success-oriented culture implies a radical denial of death and of health impairments. Middlebrook (1996, 135) is willing to change this perception:

I want the well-entrenched American denial system to change. We are taught that when a person informs us “I am dying” or “I’m in deep shit here,” we are to respond by saying, “Oh, no. No, you’re not. You’ll be fine” [...] I want a different response. I want interest and curiosity [...] I want someone to say “God, how awful. How’re you doing?”

Social perceptions that see only a complete cure as a positive outcome to illness and disability fail to recognize the value of the experience. As Middlebrook explains in detail, the chronically ill are asked to perform the role of the good patient, which implies denying the emotional toll that comes with illness or disability: “Denial is the great tsunami. Anger, suffering, jealousy, envy, fear – all are invisible far out at sea. They ride, unbidden, behind the great wave. Then, unexpectedly, denial approaches the shore, approaches where we really live.” (Ibid., 10) For her, America suffers from a denial system that makes ill people seem less worthy – people to be pitied and avoided. As a Jungian analyst, Middlebrook is acutely aware of Jung’s ideas on the need to accept death as part of life, and of the damaging effects of denying its reality. In her memoir she is determined to avoid that denial.

Already in their ironic titles both memoirs highlight the fears and contradictions of contemporary perceptions of death: “too late to die young” and “dying before I do” refer to conventional social expectations regarding illness and disability. And the authors set out to challenge those perceptions. Suffering from disease and disability, they are expected to die much sooner than they actually do. *Too Late to Die Young* refers to the idea that Johnson’s congenital disease made everybody, including herself, assume she could die at any time. Like many children with disabilities she feared she would never see adulthood, because she did not see adults with disabilities like hers. Instead of seeing her individual capabilities, everybody at the time just focused on a possible cure, getting her to walk normally, having a straight back, etc. As she grew older and older, defying her own expectations, she realized she had been a victim of fraud:

I had never been terminally ill the way I was led to believe [...] As I hear the death sentence being pronounced on another generation of children, I wonder how many have actually been killed by the predictions. Worst of all, how many have lived and died without learning to value their own lives? (Johnson 2005, 13)

What she constantly affirms throughout her memoir is the value of her own life: “While I have been expecting to die, my time has become filled with people and places and work and strange undertakings [...]. I have stories to tell and retell and stories unfolding that I want to live out.” (Ibid., 17) And among these stories many concern the pleasures of everyday life: “I used to try to explain that in fact I enjoy my life, that it’s a great sensual pleasure to zoom by power chair on these delicious muggy streets, that I have no more reason to kill myself than most people.” (Ibid., 2) She provides ample detail about her daily life and how she is not bothered by physical dependence on others. On the contrary, she remarks how this daily personal care, far from being undignified, is in many respects a deep form of comfort and connection that can even be considered a privilege:

Geneva brings me my breakfast and then gives me a bedpan and then washes me, starting with the nighttime crusts in my eyes, all the way down to the spaces between my toes, and everything in between. It’s a daily necessity, entirely practical and matter-of-fact. I sometimes think how strange it would be to do these morning things in solitude as nondisabled people do, and to regard, as many of

them do, a life like mine as a dreadful and unnatural thing. To me it is so natural to feel the touch of washcloth-covered hands on flesh that is glad to be flesh. (Ibid., 251)

Interestingly, since her disability is congenital, it is natural for her to live with that kind of body. She has not undergone any dramatic change (in contrast to someone who meets disability or illness halfway through life). She has always identified with her body and her disability. What Johnson – like Middlebrook – describes is society’s denial of her difference: she is very aware of the damage social perceptions exert on disabled people. When she meets the academic Peter Singer, she confronts his ideology on the rejection of disability: “He regards lives like mine as avoidable mistakes.” (Ibid., 219) In the logic of recognition, differences are desirable and worthy, not something to be avoided: “Disability shapes all we are [...] We have something the world needs.” (Ibid., 208)

Examples of misrecognition, and of the inadequate emotional responses that reveal it, abound in Johnson’s memoir: “I admire you for being out; most people would give up [...]. If I had to live like you, I think I’d kill myself.” (Ibid., 2) Against such attitudes, she is aware of the need to voice the perspective of disabled people on their lives. Their memoirs are counter-stories to general perceptions: “We need to confront the life-killing stereotype that says we’re all about suffering. We need to bear witness to our pleasures.” (Ibid., 253) In doing this, Johnson’s story effectively contributes to an understanding that the disabled body is, above all, a dimension of knowledge about the world (cf. Avrahami 2007, 2).

In a similar way, the subtitle for Middlebrook’s memoir, “Dying before I Do,” refers to the expectation of an earlier death. In 1990, she was told that she would live two more years. At the time of writing her memoir in 1996 she can already be ironic about that expectation, as she is now living in borrowed time (she died in 2009). Middlebrook’s sense of time and proximity to death also affects the form in which her memoir is written. For instance, it provides her book with a non-narrative structure. Time is for her “at once her enemy and her most valued resource” (Couser 1997, 73f.), so in a way she is free to dispense with chronology altogether; accordingly, as Couser (1997, 74) has demonstrated, her book is organized on other principles. “Time has lost its linear qualities,” says Middlebrook (1996, 163) as she narrates the effects of her illness. And she allows her readers to share that same sense of disruption: for Shlomith Rimmon-Kenan (2002, 19), by way of example, the reading of the memoir induced severe temporal disorientation.

Middlebrook largely structures her memoir around varied responses to her progressive illness. Sometimes she proceeds by indirection, as when she interprets her daughter’s resistance to getting her driving license as reflecting her attempt to keep her mother alive by continuing to depend on her. Her approach is often bluntly direct, cutting through the gentility and sanitization of most illness narratives to enumerate the horrible side-effects of chemotherapy. Nevertheless, what she most resents is the wrong expectations from people around her. After a terrible 18-month treatment, people find she is looking well again.

However, she knows that cancer does not stop, and finally leads to death: “Cancer will kill me. It will sneak up on me, make microscopic but lethal invasions into tiny parts of my body without my even knowing it. And while it happens, I will be looking healthy.” (Middlebrook 1996, 99) And she wants that acknowledged, not denied. What she wants is not admiration for being brave, but interest, curiosity; she longs to be asked simply, “What is it like?” (ibid., 135). She explains that the reaction she most valued was when a friend told her death is “life’s biggest transition. Go for it.” (Ibid., 209) This is the kind of empathy and recognition she longs for.

As an important part of the process of recognition, illness and disability memoirs often insist on the need to refer to the experience of cancer in precise terms, and Middlebrook does this effectively. She explores the language used to describe her cancer and perceives that health professionals sometimes hide information while appearing to give it:

I have a “spot on my spine”. In fact, three spots on my spine. “Spot”, I have learned, is camouflage for the stink words: tumor, metastasis, recurrence, progression of disease, Stage IV, inevitably fatal – words and phrases you can’t say without holding your nose. It took me a while to understand what my doctors were refraining from telling me, as though the knowledge itself were evil. (Ibid., 7)

In her language and metaphors Middlebrook bears eloquent witness to cancer. She is especially effective when she tries out different metaphors to illustrate her experience of living with it. The trope of illness as combat pervades her whole narrative: “What has happened to me? How can I make sense of it? The technology that has saved me has killed me in order to rescue me. We destroyed villages in Vietnam, too, in order to save them.” (Ibid., 77) She feels that the paradoxes, pains, and victories of cancer are like those of war. Another metaphor is the “crab” of her title, the name of the crustacean she learned to catch as a child and later taught her own children to catch: “The crab is a shifty beast, its eyes attached to its body like headlights. Like cancer, it never takes the direct path, preferring to move sideways and furtively. You learn to crab in your own way and your own time.” (Ibid., 14) Just as she once learned to catch a crab, so now she will be able to appropriate cancer and make it part of what she is. In fact, this metaphor helps explain emotional reactions, fears, rejections:

My mother [...] says *cancer* in a hushed voice. Her eyes roll upward, she flutters her eyelids [...] How old does one need to be to reach into the tidal pool and grab a crab with a bare hand? I know the primordial fear the sight of those claws, the sound of the word, elicits. (Ibid., 13, emphasis in the original)

Again, she uses the image of sailing to describe her recuperation from the devastating effects of treatment. Sailing works as an interesting metaphor in the sense that you depend on the wind to sail; and wind, like life, is not predictable: it changes, and however much you seek the illusion of control, you do not control it.

Another significant pattern in illness narratives is what Couser (1997, 185) calls the redemptive shifting of emphasis from body to mind. On the one hand, the intellectual life of the memoirists seems to provide them with a wor-

thy life, a way out of physical pain and impairment. It is what allows them to write and make sense of their experience. As most of the authors are university trained, or at least well versed in writing, they can find a certain consolation in distancing their bodies from their minds. On the other hand, this can also be read as a disembodiment of the self. It is common for illness memoirs to report that the affected body seems alien, as if it no longer belongs to the self (cf. Conway 2007, 46f.). Sometimes this sense of physical alienation reflects an attempt on the part of the psyche to protect the self from an awareness of loss that would threaten stability. It is as if the psyche cannot tolerate what has happened and therefore shuns, disowns, or repudiates part of the body (cf. *ibid.*, 50). This is also the case in Middlebrook's narrative, which often refers to the inner self as separate from the body. Thus she writes: "I was so appalled at what my body was doing to us all." (Middlebrook 1996, 16) In an attempt to defend herself and her family from the onslaught of cancer, she explains: "I could feel [...] the whole family's torture. They had thought that all of me, body *and* soul, was going to die. But I had known that if my body had to die, I was not going to accompany it." (*Ibid.*, 61; emphasis in the original) This removal of the self from a sense of connection with the suffering body is what psychologists call dissociation, a characteristic response to overwhelming trauma (cf. Conway 2007, 52). As Rimmon-Kenan (2002, 21) notes, the shifts in personal pronouns correspond to the dissociation of narrative identity. Middlebrook even refers to herself in third person, as a "zoo creature", suggesting she has lost the sense of herself as human, when she recounts the twenty-five days in which she lay in isolation during stem cell rescue:

The zoo creature is very dopey. Its left eyelid sags. Its back is covered by a hideous, pussy rash that itches [...]. Worst of all, the zoo creature cannot think or remember. It says things in a language that makes no sense. It cannot watch or understand a video [...]. It does not know what day it is or whether it is day or night. (Middlebrook 1996, 55-56)

The deep connection of the damaged body with a damaged sense of self is abundantly evident in Middlebrook's memoir. She is highly aware of what goes on in the life of her body and mind / psyche and reflects on the difference between the two dimensions:

I had not stayed inside my body to suffer the death of every fast-growing cell. My body was a poisoned wreck [...] To save myself, I, the me of me, retreated to a far corner above the room [...] I found a large psychic cloak and gathered my endangered identity within. Who I am could not endure the torture of that room. (*Ibid.*, 62; emphasis in the original)

In this painful situation, the only thing that saves her is others: "Without the periodic witness like James or Jonathan, who knew who I was, I could not know myself. Not to know oneself is to die." (*Ibid.*). Here recognition becomes self-recognition, but this is made possible only through the presence of others who acknowledge one's identity, who make the broken identity real and one:

Like the lucky soldiers in war, like some physically abused children, some concentration-camp survivors, I am still here. We lucky ones who have not gone mad have had witnesses who bore the truth when we could not. I think that's the only way the soul survives. (*Ibid.*, 72)

The chapter entitled “Witness” is, then, at the very heart of Middlebrook’s memoir: she survives as the person she is because she is “blessed with sympathetic witnesses” (*ibid.*, 62).

Since illness and disability are some of the most universal of experiences, readers may readily connect with Middlebrook’s sense of frustration at the lack of understanding and recognition from people around her. Although narrators of illness sometimes criticize the conduct of physicians, friends, and acquaintances, they rarely find fault with that of relatives. Middlebrook, however, breaks the taboo on criticism of family members to take issue with the responses of her sister, who remained distant, and her mother, who remained in denial. Her narrative is, in fact, penetrated by a pervasive sense of abandonment on the part of her family. Her father killed himself when she was 21 and away in Scotland, and the detachment of her family did not even account for a plane ticket to enable her to attend the funeral. More generally, Middlebrook takes advantage of the “privilege of the condemned” (Couser 1997, 74) to indulge in behavior generally discouraged; she vents her anger, less at her predicament than at the failure of others to acknowledge its seriousness. In a humorous tone, she describes how many assumptions made by people about her really drove her mad. She calls it, in the relevant chapter heading, going “Fruit City Bananas”:

If anyone second-guesses the decisions I’ve made (“If the odds are so bad, why go through a bone marrow transplant?”), if anyone suggests that my realistic attitude about my prognosis is wrong (“Hey, Christina, think positive”), or, worst of all, if anyone underplays the severity of the illness I have or of the treatment I have endured (“But I heard you got out of the hospital earlier than expected”), if any of this language is used, I go wild, nuts [...]. (Middlebrook 1996, 122f.)

However, the painful process of self-definition and self-recognition she undergoes through her writing enables Middlebrook to give an overall positive picture of her life. Where Johnson stated that disabled people had something “the world needs”, Middlebrook acknowledges that she has experienced blessings that healthy people may not really appreciate: “Hideous as it is, cancer has bathed me with love. Healthy people [...] can live life so unaware of love that we don’t feel it until we trip over it. We don’t see it until we fall flat on our faces.” (*Ibid.*, 120)

## 5. Conclusion

These two moving and well-written memoirs show above all how Middlebrook and Johnson promote narrative empathy through their quest to be recognized and valued on their own terms. The intensity of their prose, the sharing of intimacies, as well as the strength of their metaphors and their explicit demands for understanding, are powerful means to share their perspective with the reader and to communicate a closer experience of illness and disability. These texts make specific emotional and ethical claims on their readers, to transform

them in turn into sympathetic witnesses to lives lived with severe illness or disability. The empathic understanding that these memoirs see as their cultural task may then reach contemporary social prejudices. As Nancy Mairs (1996, 100) argues, “what is critical is an understanding of the realities disability imposes, and the only way finally to develop the necessary empathy is through knowing disabled individuals.”

Illness and disability memoirs, through their unique deployment of both theoretical and experiential vantage points, may be able to move their readers, promote self-reflection, and challenge preconceived notions concerning health, illness or disability. Ultimately, a theoretical framework that focuses on readers’ modes of engagement in the reading process (recognition, knowledge, enchantment, shock) will help us see how “literature changes our understanding of ourselves and the world as well as its often visceral impact on our psyche” (Felski 2008, 16). We may then be better equipped to recognize that the most painful traces are not those left by disease or disability itself, but by what being ill or disabled means in the collective consciousness.

## Bibliography

- Agosta, Lou (2014): *A Rumor of Empathy. Rewriting Empathy in the Context of Philosophy*. London.
- Avrahami, Einat (2007): *The Invading Body. Reading Illness Autobiographies*. Charlottesville, VA / London.
- Baena, Rosalia (2016): “No Pity. Disability Memoirs and Narrative Empathy in Robert Murphy’s *The Body Silent* and Reynolds Price’s *A Whole New Life*”. In: *Concentric* 42 (No. 2), pp. 65-83.
- Baena, Rosalia (2017): “Narrative Empathy and Illness Memoirs: Arthur Frank’s *At the Will of the Body* and Kathlyn Conway’s *Ordinary Life*”. In: *Medical Humanities* 43 (No. 3), pp. 177-184.
- Conway, Kathlyn (1996): *Ordinary Life. A Memoir of Illness*. New York.
- Conway, Kathlyn (2007): *Illness and the Limits of Expression*. Ann Arbor, MI.
- Couser, G. Thomas (1997): *Recovering Bodies. Illness, Disability and Life Writing*. Madison, WI.
- Couser, G. Thomas (2009): *Signifying Bodies. Disability in Contemporary Life Writing*. Ann Arbor, MI.
- Felski, Rita (2008): *The Uses of Literature*. Oxford.
- Garden, Rebecca (2010): “Disability and Narrative. New Directions for Medicine and the Medical Humanities”. In: *Medical Humanities* 36, pp. 70-74.
- Garden, Rebecca (2015): “Who Speaks for Whom? Health Humanities and the Ethics of Representation”. In: *Medical Humanities* 41, pp. 77-80.
- Hawkins, Anne Hunsaker (1993): *Reconstructing Illness. Studies in Pathography*. West Lafayette, IN.
- Jurecic, Ann (2012): *Illness as Narrative*. Pittsburgh.
- Johnson, Harriet McBryde (2003): “Unspeakable Conversations”. In: *New York Times Magazine*. (16.02.2003). URL: [www.nytimes.com/2003/02/16/magazine/unspeakable-conversations.html](http://www.nytimes.com/2003/02/16/magazine/unspeakable-conversations.html) (17.08.2017).
- Johnson, Harriet McBryde (2005): *Too Late To Die Young. Nearly True Tales from a Life*. New York.
- Keen, Suzanne (2013): “Narrative Empathy”. In: Peter Hühn et al. (eds.), *The Living Handbook of Narratology*. Hamburg. URL: <http://www.lhn.uni-hamburg.de/article/narrative-empathy> (17.08.2017).
- Lindemann Nelson, Hilde (2001): *Damaged Identities. Narrative Repair*. Ithaca, NY.
- Mairs, Nancy (1996): *Waist-High in the World. A Life among the Nondisabled*. Boston.
- Middlebrook, Christina (1996): *Seeing the Crab. A Memoir of Dying Before I Do*. New York.

- Rimmon-Kenan, Shlomith (2002): "The Story of 'I': Illness and Narrative Identity". In: *Narrative* 10 (No. 1), pp. 9-27.
- Sakalys, Jurate A. (2000): "The Political Role of Illness Narratives". In: *Journal of Advanced Nursing* 31 (No. 6), pp. 1469-1475.
- Schmitt, Arnaud (2017): *The Phenomenology of Autobiography*. New York.
- Taylor, Charles (1994): "The Politics of Recognition". In: Amy Gutman (ed.), *Multiculturalism*. Princeton, pp. 25-73.

Rosalía Baena  
Associate Professor of English  
University of Navarra, Spain  
E-mail: [rbaena@unav.es](mailto:rbaena@unav.es)

**How to cite this article:**

Baena, Rosalía: "Recognition and Empathy in Illness and Disability Memoirs. Christina Middlebrook's *Seeing the Crab* and Harriet McBryde Johnson's *Too Late to Die Young*". In: *DIEGESIS. Interdisciplinary E-Journal for Narrative Research / Interdisziplinäres E-Journal für Erzählforschung* 6.2 (2017). 1-13.

URN: [urn:nbn:de:hbz:468-20171121-110006-5](https://nbn-resolving.org/urn:nbn:de:hbz:468-20171121-110006-5)

URL: <https://www.diegesis.uni-wuppertal.de/index.php/diegesis/article/download/281/423>



This work is licensed under a [Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License](https://creativecommons.org/licenses/by-nc-nd/4.0/).

---

<sup>1</sup> I would like to thank Professor Ana Marta González and the CEMID research group from the Institute of Culture and Society at the University of Navarra for financial and academic support for this research project.

<sup>2</sup> In a similar vein, other scholars have recently claimed that closer critical attention should be paid to "personal and affective responses to texts" (Schmitt 2017, 161).