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**The Cartography of Pain: Spatial, Social, and Biographical Disorientation in
Suzanne E. Berger’s *Horizontal Woman: The Story of a Body in Exile* (1996)**

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10 This article deals with the concept of disorientation as intrinsic to the experience
11 of chronic pain and disability, implying the disruption of spatial directionality and
12 biographical continuity. This experience of spatial and existential displacement is
13 the critical point of Suzanne E. Berger’s chronic pain memoir *Horizontal Woman:*
14 *The Story of a Body in Exile* (1996). Building upon Sara Ahmed’s
15 phenomenology of orientation, this essay looks into two dimensions of the
16 experience of disorientation narrated by Berger: (1) the dismantlement of the
17 familiarity with the domestic realm and the transformation of affective
18 relationships in that space; (2) the impact of illness and disability in the public
19 world and the dynamics of power between “straightness” and otherness. The
20 textual analysis concludes with a reflection about the regained sense of possibility
21 or potential for change that biographical writing brings to the ill subject.
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42 Keywords: horizontal; disorientation; chronic pain; Suzanne E.
43 Berger; memoir
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55 **Introduction: The disorientation of the body in pain**
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58 Sara Ahmed explains in *Queer Phenomenology* (2006) that to be oriented implies
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1 “find[ing] our way in a world that acquires new shapes, depending on which way we
2 turn” (1). This affirmation is particularly concerned with how bodies shape and are
3 shaped by the surrounding world in the context of sexual orientation. However, the
4 contribution of Ahmed’s phenomenological project goes beyond rethinking sexual
5 orientation as “a matter of following a direction or ‘being directed’ in a certain way”
6 (21). This theorist certainly provides phenomenology with innovative theoretical
7 instruments to address the experience of orientation in a broader sense. In this new
8 phenomenological scope, materiality acquires prominence in the discussion of
9 embodiment and orientation, as the materiality of both body and space determines how
10 subjects turn toward the world. As Ahmed explains, the orientation of the body depends
11 on factors like gender, sexuality, race, and religion. Physical disability and (chronic)
12 illness should be added to these markers, as these embodied conditions govern
13 orientation not only in the spatial sense, as in cases of limited mobility, but also in the
14 ways in which the disabled bodies navigate the social world. In this article, I
15 reformulate the initial question posed by Ahmed in *Queer Phenomenology* into: “What
16 does it mean to be oriented for the disabled and chronically ill subject?” Finding one’s
17 way is an embodied act and for that reason we must answer the question of how
18 subjects are oriented even when they experience their bodies as obstacles to carrying out
19 their projects in the world.

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Orientation is the movement of bodies or objects toward something, a sense taken for granted when they follow the (normative) paths others followed before them. Disorientation implies having strayed off those given paths. Ahmed calls this sense of disorientation “queer moments,” when the world appears “slantwise” (65). If subjects are oriented when they make sense of space, disorientation is the loss of coherence between body and space. The onset of unexpected illnesses or disabilities can be

1 considered queer moments, but in an alienating sense. Although Ahmed does not refer
2 to the experience of bodily dysfunction in her work, queer phenomenology and the
3 study of dysfunctional embodiment or impairment may go hand in hand. The objective
4 of queer phenomenology, as envisioned by Ahmed, is to “offer a different ‘slant’ to the
5 conception of orientation itself” (4). Disability and illness certainly “slant” the subject’s
6 perception of the familiar world. However, rather than revealing new experiences of
7 proximity or contact with other bodies and objects or generating new forms of
8 participation in the world, experiences like chronic pain may rupture one’s sense of
9 orientation completely.
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21 American poet Suzanne E. Berger’s memoir *Horizontal Woman: The Story of a*
22 *Body in Exile* can be considered an example of autobiographical narrativization of the
23 experience of embodied disorientation. Published in 1996, *Horizontal Woman* was
24 Berger’s first autobiographical work in prose, presented as a collection of essays and
25 preceded by two collections of poetry: *These Rooms* (1979) and *Legacies* (1984).
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27 Despite its richness of poetic imagery and language and its multilayered narrative
28 structure, Berger’s memoir has undeservedly received little academic attention, a lacuna
29 that suggests the marginal situation of certain illness stories. Both chronic pain and
30 functional disability are intermingled in this autobiographical narrative, which can be
31 considered both a chronic pain memoir and a disability memoir. However, to avoid
32 contributing to erasure of chronic pain as an illness—in contrast to acute pain as a
33 symptom—this essay considers Berger’s account as a chronic pain memoir, since in her
34 particular case disability is contingent to pain. Berger’s book assimilates conventions of
35 both disability and illness memoirs. Similar to many other disability memoirs, Berger
36 portrays a reality that confronts the ableism of normative culture and its power to
37 stigmatize bodies. Although Thomas Couser argues that, unlike disabilities, most
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1 illnesses are not stigmatic (177), chronic pain can bring about complex stigmatizing
2 responses related to its invisible nature and its social (and medical) delegitimation, as
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4 Jean Jackson suggests in the title of her article “After a While No One Believes You.” It
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6 seems necessary, therefore, to acknowledge Berger’s chronic pain as the nucleus of her
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8 story and disability as the expression of illness, two experiences that point to the long-
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10 lasting effect of dysfunction in the sufferer’s biography.
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14 Berger’s narrative voice tells her life as the horizontal woman, offering a “slant”
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16 perspective of a world that turned unfamiliar and threatening. “Something happens,”
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18 Berger writes, “and then the world spins on a new axis” (xv). Due to a sudden injury she
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20 suffered to her low back when trying to pick up her child, she was no longer able to
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22 hold or balance her body upright without feeling extreme pain. Unable to walk or sit
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24 down, her wounded spine forced her to adopt a horizontal position in public and private
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26 spaces, which she combined with intermittent moments of verticality and partial
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28 mobility. Spatial disorientation soon mutated into existential disorientation, since not
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30 only was her body damaged, but also her being-in-the-world: “The body is a world; the
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32 reference points are motion and self-knowledge, physical habit and predictability. When
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34 those points ‘flicker,’ the owner is in existential dislocation” (52). Living horizontally
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36 for ten years, Berger’s body in pain inhabited a world that lost its order, feeling like a
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38 foreigner among the upright.
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46 The particular experience of pain this author chronicles points to a strong sense
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48 of embodied disorientation. Pain is not simply the response to a noxious stimulus. As
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50 Christian Grüny argues, pain is a counter-movement. The urgency of withdrawal incited
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52 by pain is blocked because even though sufferers want to escape painfulness they find
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54 “no way out.” The restriction of intentionality for Berger, however, is more complex
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56 due to the disabling nature of her pain in the vertical axis. Her account revolves around
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1 the experience of “I cannot”: “I *can’t* stand up for long without help, I *can’t* walk for
2 more than a few feet: using a wheelchair is difficult because I *can’t* sit up for any useful
3 length of time” (xv; emphasis added). Her experience of disorientation is related to the
4 centripetal directionality of pain, as Drew Leder calls it. The body becomes “the center
5 or axis of thematic attention,” dragging the subject inward rather than outwards toward
6 the world (“Toward a Phenomenology” 255). The world of the subject in pain shrinks,
7 not only because pain absorbs their attention, but also because it influences (motor)
8 intentionality. Leder notes that “we literally cannot move” or “we cannot move without
9 increasing the pain, and accept a restriction of movement to restrict our suffering,” and
10 “[e]ven if we can move, our range of motion is now all in reference to a single axis
11 point” (256). Berger’s single axis point is her lower back, which imposes the same
12 restrictions regarding intentionality and mobility in both vertical (painful) or horizontal
13 (painless) position.

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31 Verticality, orientation, and intentionality—three key concepts of Merleau-
32 Pontian phenomenology revised by Ahmed—are essential to understand the illness and
33 disability experiences narrated by Berger. The subject’s sense of spatial orientation
34 depends on the coherence between the vertical and horizontal axes, which coordinate
35 what Merleau-Ponty defines as the “spatial level” (289). However, as Edward Casey
36 notes, a disturbance in the vertical axis is more disorienting than the “confusion
37 concerning right-left and front-behind locations” (79). To be oriented implies a strong
38 sense of bodily verticality, since the vertical axis sets one’s embodied directionality,
39 whereas the horizontal axis is the field of that directionality (Todes 123). Straightness—
40 in the sense of uprightness—is not inherent to the bodily physical structure, as Merleau-
41 Ponty points out: “We remain physically upright not through the mechanism of the
42 skeleton or even through the nervous regulation of muscular tone, but because we are
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caught up in a world” (296). Yet this alignment to the world still demands an implicit effort on the part of the subject.

Straightness necessarily depends on balance. “Balancing ourselves,” Samuel Todes explains, “we *are held* vertically upright by the way we *hold ourselves* upright in relation to the steady vertical field of influence in which we stand” (125; emphasis in the original). The loss of balance implies the loss of uprightness, and therefore the loss of orientation. As Berger narrates in her memoir, her injured spine compromises her involvement in the world and the phenomenological sense of “I can.” Without balance, the horizontal axis is no longer a field that “presents us with our needs for useful objects” upon which we can act (126). Instead, the subject becomes an object among others in the horizontal field (Merleau-Ponty 296). In this context, S. Kay Toombs asserts that being “unbalanced” or “off balance” and the consequent loss of agency implies being “vulnerable within the world” (“Sufficient” 15). In her self-story, Berger insists on her vulnerability as the horizontal woman, both in physical terms and in the sense of being the object of social judgement. From her horizontal position, she cannot control the way in which her body interacts with the environment, which she experiences as strange and dangerous.

Berger narrates her non-normative relationship with space and encourages readers to see the world through the eyes of the horizontal woman. She tells how she is no longer caught *up* in a world. Instead, in her horizontal position, she is caught *in* a world made by and for the upright/abled subjects. In view of those experiences, Ahmed’s queer phenomenology can be used to analyze this type of narrative about experiences of disorientation related to pain, loss of mobility, and the disrupted sense of social situatedness. Ahmed herself emphasizes the function of a queer phenomenology as a “disorientation device” (172), as it offers a scope that contributes to challenging the

1 notion of space in its embodied, social, and political dimensions. Berger's account, in
2 fact, effectively functions as a disorienting literary instrument that opens up a new angle
3 of experience and contests the taken-for-granted notions about the upright world,
4 revealing that world's exclusionary powers.
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9 In this regard, this article looks into two dimensions of the experience of
10 disorientation narrated by Berger. The first part of the analysis considers disorientation
11 in the domestic space, focusing on the reorganization of the familiar geographies, as
12 well as the reworking of the affective orientations between Berger, her husband, and her
13 daughter around dependency. The second part explores the consequences of
14 disorientation in the public realm, where the misalignment between the horizontal and
15 vertical axes represents a complex set of dynamics of social exclusion. Finally, the
16 textual analysis concludes with a reflection about the value of illness narratives as
17 vehicles of biographical regeneration.
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31 **The domestic disorientation of the body in pain**

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33 The domestic space, rather than the institutional space of hospitals, is the individualized
34 space for long-term illness, (self-) care, and convalescence. However, the experience of
35 this realm as a place of "privacy, security, independence and control" is as fragile as the
36 bodies that inhabit it (Imrie 746). Pain and illness can destroy familiarity with the
37 domestic space. In her autobiographical account, Berger is especially concerned with
38 two forms of disorientation related to the loss of balance caused by chronic pain. On the
39 one side, her loss of balance in the vertical axis makes her relationship with the physical
40 space of her home a dysfunctional one and, on the other, her dependency on the help of
41 others to perform everyday tasks knocks the family structure off balance. Both types of
42 domestic dislocation imply the disintegration of Berger's personal identity as an
43 autonomous subject.
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Berger's account explores the alteration of the (functional) familiarity with the domestic space, expressed in the discordance between the materiality of the ill body and the materiality of the domestic world, which becomes obstructive and restrictive. In Berger's self-narrative, "home" changes its meaning with chronic illness and loss of mobility, a phenomenon that Toombs also notes, drawing upon her own experience with multiple sclerosis: "the hitherto familiar world is permeated with a global sense of disorder. It is a world in which one is no longer at home" (*The Meaning* 97). The world has a vertical order, which is given: that is, it exists regardless of one's embodied orientation. It is precisely in this "givenness" that the body can act and be "at home" in the world. Berger explores the experience of the domestic space from a queer angle, proving that the verticality of the world is not actually given, but made by and for the able-bodied, favoring the dislocation of non-normative bodies. Her horizontal experience exposes how architecture—designed taking an upright, healthy body as the normative model of corporeality—contributes to her domestic disorientation and feeling of unfamiliarity.

The section "Invisible Geography" (1–39) includes several chapters in which Berger retells her housebound experience. The author borrows the expression "invisible geography" from Scarry's *The Body in Pain* (3) to underpin her own map of pain. Although this concept originally refers to the intersubjective conflicts posed by pain—analyzed in the next section of this paper—Berger's use emphasizes the spatial experience of the body in pain. "Invisible geography" denotes the metaphorical territory of suffering of the subject in pain, who feels trapped and isolated from the rest of subjects. This metaphorical space tends to be associated to the domestic sphere, a place where pain can be expressed openly, as the sufferer is sheltered from the social restrictions regarding pain behavior. This invisible geography, therefore, is

1 paradoxically visible, as Berger's house undergoes several modifications to adapt to her
2 new horizontal position, as she describes in the chapter "House Tour" (28–35), in which
3 she guides readers through the horizontal woman's house. This atypical tour explores
4 the domestic drama of her horizontal existence in a house built for vertical living.
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9 Berger prefaces "House Tour" with a verse extracted from Philip Schultz's
10 poem "Wings": "I am this body & the weather all year round" (28). This reference
11 renders in verse two of the main affirmations of phenomenological philosophy:
12 existence is embodied (self and body cannot be dissociated) and existence implies our
13 immersion in the world (our embodied selves are not detached from the "outer" world).
14 In Shultz's terms, we are our bodies because our sense of being depends on the
15 communion of self and body, and we are the weather because we can experience it by
16 *being in* the world. Berger reinterprets and uses this weather motif to begin her house
17 tour. She starts depicting the exterior of her house but from the inside, describing her
18 view through the windows. Berger's point of view is restricted to observation rather
19 than experience, as she is not a participant in the outside world, which changes with the
20 seasons while she remains housebound due to her fear of being "stuck" outside, unable
21 to return to the house, "the ambiguous sanctuary with the too familiar couches and
22 floors inside—the house not left for weeks, for those weeks the walls the only view"
23 (29). Berger anticipates the drama of *being* a horizontal body and the spatial fracture it
24 causes contrasting the inaccessible outside world that is threatening and the domestic
25 world that often becomes unhomely and monotonous.
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51 Inside the house, Berger guides readers from the first floor—the space of
52 convalescence—to the most inaccessible space—the attic. She selects specific places in
53 the house and examines them individually through the prism of disability. As she
54 ascends through the house's vertical axis, Berger describes the adaptations done to these
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1 spaces, mainly on the first floor. When Berger refers to these modifications she uses the
2 passive voice, which is significant from a textual perspective, as it seems to conceal the
3 literal passivity of her horizontal position, while implying that these adjustments were
4 made by the able-bodied members of the household: “Often, more often than in other
5 houses, paintings are transposed, photographs switched, throws and pillows moved from
6 here to there and back, trailing their memorized pattern behind. The colors of the walls
7 are changed too” (30). Berger insists throughout the chapter on her efforts to avoid
8 experiential monotony. However, as she moves around the house, one realizes that her
9 domestic disorientation is closely related to the functionality of spaces and objects and
10 her bodily dysfunctionality. The reorganization of the domestic space to adapt it to her
11 horizontal body is articulated around what Corbin and Strauss call “ill-related work,”
12 defined as the “regimen work, crisis prevention and management, symptom
13 management, and diagnostic-related work” (226). The ill-related work performed by
14 Berger consists in maintaining a horizontal position as a mechanism to prevent painful
15 movements and re-injury. Ahmed’s definition of work, in this sense, can be applied to
16 this specific case of spatial reorientation:
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40 Work ... involves adjustments: we might move this way or that, so we can
41 work with this or that object: work involves a direction toward the object,
42 which then works for us. The failure of work is not, then, “in” the thing or
43 “in” the person but rather is about whether the person and the thing face
44 each other in the right way. (50)
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54 The spatial conflict experienced by Berger is related to the impossibility of facing
55 objects in “the right way,” provoking the loss of their particular functions. To solve the
56 failure of work, the objects are reoriented to accommodate them to the horizontal body.
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This is expressed in Berger's portrayal of her (sick)bed, alternatively located in the dining or living rooms:

a double bed is placed close to the dining room table, a bed first used for eating, resting, playing cards lying down, for sleeping on the first floor, for the smooth music of physical therapy's score; then for reading and playing children's games, then, much later, for sleeping away from conflict and harsh mutual decisions, for brooding in summer, with the door to the small porch wide open to clarity or solution. (30)

For Berger, the delocalization of the bed not only alters the meaning of space, but also reflects her disability's progression: the more chronic her injury becomes, the more multifunctional the bed and the surrounding space are. In this sense, this reorganization of space results in the "slant," rather than "right" alignment of body and objects, because the horizontal and disoriented body is an object among others in the horizontal field. In "Snack Bar", for example, behind the humorous self-portrayal of her body covered by appetizers after a table leaf fell over her, Berger captures her immersion in the horizontal axis and her eventual transformation into an object: "the amazing living snack bar" (12). Since there is not an "intimate co-dwelling" of the body with objects (Ahmed 52), the horizontal body cannot experience them despite being *in* the horizontal field.

This type of disorientation illustrates the implicit nearness of objects to the body in the sense of "I can"—the embodied capacity to act is what makes objects approachable. In her horizontal position, Berger lives in a constant sensorial and experiential monotony, which she poetically expresses in her description of the ceiling of

1
2 her bedroom, a space that is overlooked by the upright, but becomes the only view
3 available from her horizontal perspective:

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5 starred with random flecks of gold metal that fall sometimes, ceilings to
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7 contend with, viewed constantly. The visual staccato of this gold means the
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9 eyes can never rest; there is no constellation or pattern to follow. ... And *if*
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11 there is a music for the whole ceiling-skin of the house, it is Philip Glass,
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13 further flattened, the same note played over and over. (34–35; emphasis in
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15 the original)
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22 Despite being adapted to disability, her house does not represent the extension of bodily
23 action, something that is reflected in its colorlessness: “The house can seem like an
24 aquarium with seasons inside, moving slowly through like plant filaments” (29). The
25 image of the aquarium is a recurrent metaphor. In this specific excerpt, the
26 house/aquarium analogy has two contrasting meanings for the horizontal woman: it is a
27 safe container for vulnerable creatures that cannot survive in the natural environment,
28 but it also carries a strong sense of deprivation of freedom. Berger’s sense of
29 entrapment, however, does not solely emerge from the domestic realm, but also from
30 her own body in pain, as she reflects in her poem “House of the Body” which she
31 includes in the second part of her memoir, “Rehabilitation Blues” (41–109). This poetic
32 piece reflects the feeling of unhomelikeness of the subject in pain and the
33 spatiotemporal distortion of embodied experience: “There are vestiges of lost motion in
34 you, / and filaments of desire: / the world constricts to the size of pain” (43). Both the
35 domestic space and the body seem to be strongly alienating for the author, the former
36 for being vertical and the latter for being horizontal.
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The house's staircase, which architecturally symbolizes the spine that sustains the vertically erected house, is the main obstacle in Berger's domestic experience. To ensure accessibility, an elevator chair is installed. Yet, despite allowing vertical mobility, the use of this machine also contributed to her experience of disorientation:

The rides were offered in the spirit of sharing the amazing grace of upward ascension without physical effort, the almost bodiless floating feeling, despite seeing oneself as the elderly person in the ads, going up, with the sound of flying saucers and flying witches. (32)

Without actually using the stairs or moving her body to go from the first to the second story, the chair user becomes completely passive as there is no *interaction* between corporeality and space, transforming this domestic zone into a disembodied space. Ascension without physical movement is experienced as a "bodiless" act. Berger's lived body is transformed into an object-body transported by the chair. Although she can express her embodied intentionality, it does not emerge from her own motor capabilities. When considering interaction with the surrounding world, Ahmed argues that "[t]he actions performed on the object (as well as with the object) shape the object," which "in turn affects what we do" (43). In cases of bodily dysfunction, it can be said that the object may also shape the (embodied) identity of the disabled subject, as in the case of wheelchair users. Rather than regarding the electric chair as an extension of intentionality, Berger looks at it with resentment and acrimony. The memoirist's attitude toward her own disability shapes and is shaped by her negative view of both the staircase space, characterized by its "unsurpassed but possibly redeemable ugliness," and her electric chair, which she describes as a "beast to be summoned to labor," nicknamed "the Chair-O-Later, The Electric Chair, the Spielberg machine, and

1 the Magical Mystery Chair” (31). Berger chooses sarcasm and dark humor in the
2 portrayal of this visible marker of disability as a product likely to be advertised in “As
3 Seen on TV” infomercials—similar to the infamous Flex-O-Ladder—or as an
4 instrument of torture and method of execution by electrocution. However, this author
5 also seems to view the chair in a more positive light, as its vertical ascension and
6 “extraterrestrial sounds” (18) evoke Spielberg’s science-fiction movies, while the afloat
7 sensation of being transported recalls the hallucinatory feeling of flying associated to
8 psychedelia, which Berger implies in the reference to The Beatles’ *Magical Mystery*
9 *Tour*, a film and record created during the band’s experimental period in the sixties.
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21 The loss of motor functions entails one’s dependency on objects that enable
22 mobility, as well as on people who provide the chronically ill and disabled person with
23 care. Dependency is often attended by informal caregiving, the care practices performed
24 by a member of the ill or disabled person’s family in the domestic realm. For adults, this
25 type of caregiving, contributes to the disorientation of the dependent subject in the
26 relationships with other bodies that cohabit the house with them. This disorientation in
27 the *normative* family structure emerges from the disequilibrium of the vertical or
28 hierarchical system in which the parents (ideally in a coequal role) are the care-givers
29 and providers, while the children assume a dependent role—a model that is reversed
30 when parents age and become part of the group of “the elderly.” A parent’s illness or
31 disability dismantles the family structure, as the dependent person is displaced from the
32 highest point of the vertical axis to the horizontal field of dependency, a space shared
33 with their children. This new orientation in the familiar space becomes oppressive for
34 both the caregiver and the dependent adult, since it is based on an unequal relationship.
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36 In the chapter “Gratitude/Chiaroscuro” (90–98), Berger asserts that gratitude for
37 caregiving is the core factor in the disparity between her and her husband, since needing
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constant help from others implies being in a lower position in the newly established domestic order:

Gratitude is the good behavior extracted from the recipient of multiple kindnesses: a form of bitter payment between adults, who—while honorable and fair-minded—are trapped. As times goes on, giving gratitude becomes a labor in itself, when one person is always *doing* and the other receiving. (92; emphasis in the original)

This new type of relationship disconcerts Berger, as the roles performed in the past, based on her autonomy and ability to act, are overtaken by her dependency on the goodwill of her husband. However, this dependent relationship is more disorienting for her than for her husband since while he can change the directionality of his actions escaping his caregiving responsibilities Berger is stagnant in her dependent role:

Easy for him to walk away to work, to run, to pick up his child: he doesn't have to lie here in a whirlpool of physical change and self-pity and a feeling of helplessness. He doesn't have to feel grateful every minute of every day.
(92)

Informal caregiving wears down her marriage, as Berger's perspective as a care-receiver reveals that there is no real reciprocity between the disabled and able-bodied counterparts, as overused gratitude loses its meaning and the dependent subject develops a strong sense of personal devaluation.

This imbalance in the family structure has a major consequence in her mothering role, especially when dependency is judged against the ableist model of motherhood. Berger tells how dependency compromised her identity as a mother, even though she was able to re-accommodate her affective orientation toward her daughter to offer

1 “emotional protection” and “physical affection” (185), which were performed from a
2 queer angle, either in the horizontal field or in brief moments on the vertical axis:
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5 when I rise for the occasion of kissing my child as she stands on a stool, so
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7 that I won’t have to bend, it is ecstasy. The old angle of self meets the curve
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9 of normal love: the curve of her cheek meets the angle of my unusual
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11 motherhood. I am momentarily in the land of the upright. (37)
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17 Berger is able to successfully reorient herself in the world and toward her daughter’s
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19 body from the angle of disability. Yet this non-normative motherhood is a source of
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21 self-judgment—as Berger admits that she is unable to provide her daughter with
22
23 physical protection in the chapter “Running” (3–5)—and social judgment, as her
24
25 horizontal motherhood is the object of social misinterpretations and discrediting:
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30 when an arrogant young teacher once suggested that my kindergartner was
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32 being ‘parenticized,’ that is, taking the role of parenting the parent because I
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34 was disabled, the claws came out. In our house, no one was allowed to tell
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36 her to take care of her mother. (186)
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41 The teacher suspects a family crisis caused by Berger’s disability, a myth that surmises
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43 that “disabled mothers not only fall short of ideal mothering, but that they depend on
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45 their *children* for care and services, exploiting these ‘young carers’ and robbing them of
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47 their childhoods” (Malacrida 10). Social interactions like this one shed light on the
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49 ideology of motherhood, proving that the sense of failed or disoriented motherhood is
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51 not directly rooted in the experience of disability, but in the social pressure that
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53 advocates an ableist archetype of motherhood. As explained in the next section, in the
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55 social world, Berger not only encounters architectural obstacles that restrict her
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1 navigation in public spaces, but also ideological and discursive barriers that obstruct her
2 orientation toward other subjects and exclude her socially.
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6 **The social disorientation of the body in pain**

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9 The social judgments and intersubjective conflicts that Berger faces outside the confines
10 of her own home are mapped onto what Elaine Scarry calls the invisible geography of
11 the body in pain. As Scarry explains, pain has “no reality because it has not yet
12 manifested itself on the visible surface of the earth” (3). Although pain is a reality for
13 the suffering person, its social recognition depends on whether others believe the person
14 in pain or not. Communication, or rather the failure to communicate, is the factor that
15 maps the invisible geography of pain. Unlike other experiences, pain evades language,
16 as it “runs dry” in the sufferer’s mouth when trying to explain physical suffering, as
17 Virginia Woolf poetically explained (15). Even with the use of figurative language to
18 compensate for the linguistic resistance, pain sufferers often feel others do not fully
19 understand them, as if they speak a different language. As Berger herself notes, “the
20 psychological states of the isolated person, the person who is doubted and can speak
21 only in these strange tongues, are often expressible only by comparison” (50).
22 According to her own experience, the failure of communication is ingrained not only in
23 the difficulty to put pain into words, but also in the negativity of the pain expressed by
24 means of figurative images that often alienate the listener:
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49 I began to associate moods with lower forms of life, with amoebas, slugs. ...

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51 “How can you say you feel like a slug?” people would ask. I could never
52 explain that it wasn’t a cruel or belabored comparison, just the truth: another
53 illustration of the failure to communicate in an acceptable comradely way.
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Although expressing a reality for the sufferer, this image may be (mis)interpreted by others as a grotesque exaggeration that may forestall compassion and empathy with the sufferer: “Since pain can neither be verified nor denied in many cases, the person in pain is doubted—are you malingering or overdramatizing?—which only then amplifies the pain. With only vivid, but subjective comparisons to ‘defend’ ourselves with, we can hardly communicate at all” (49). Berger, unable to share her pain with others, feels isolated, and, in turn, social doubt and uncertainty push her away from the public space. She explores this idea in her reinterpretation of Rainer Maria Rilke’s poem “The Panther,” which she uses to express her experience of existential disorientation. Her identification with the caged panther is a powerful image that captures pain’s ability to absorb the subject: “We [chronic pain sufferers] became like Rilke’s panther, pacing the cage of each individual problem, with the coldest iron bars seeming to separate us from [the rest of subjects]. ...[S]ome saw ‘a world made of bars, a thousand bars, and behind the bars, nothing’” (80). The image of the chronic-pain sufferer pacing the cage of illness does not simply reinforce the idea of social isolation, but also the notion of self-absorption related to the centripetal directionality of chronic pain, which draws the sufferer inwards, while the outer world, behind the bars of the body/cage, becomes experientially empty.

Credibility, however, is not limited to verbal communication. Berger recounts the social conflicts caused by the invisibility of the source of her pain and the hyper-visibility of her pain behavior expressed through her horizontal position and disability “accessories”—her cane and wheelchair. As her illness progresses, Berger combines moments of horizontality, verticality, mobility, and disability. This behavior can be defined as the expression of what Susan Sontag defines as the “dual citizenship,” related to health and illness:

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Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (3)

Berger's body in pain subverts the self-exclusivity of those kingdoms, becoming the object of social delegitimation. As Claire Glenton notes, chronic back pain sufferers reside in a liminal space, "being both well and sick, and being neither" (2,244). In fact, using a wheelchair and being able to walk short distances, as Berger does, are two behaviors that do not match the expectations regarding both health and disability.

According to Ahmed, orientation implies the subject's participation in "a longer history in which certain 'directions' are 'given to' certain places" since, building upon Edward Said's orientalism, geographies are "man-made" (Ahmed 113). Similarly, both Scarry and Sontag do not describe a "real" geography, but rather the political and cultural discourses constructed around pain and illness, respectively. For the ill and disabled person, the world seems to be made *by* and *for* the able-bodied, that is, "the world of strength, the positive (valued) body, performance and production, the non-disabled, and young adults" (Wendell 40). In this context, Berger narrates the social response to the presence of a chronic pain sufferer and disabled woman in a world dominated by the culture of health and able-bodiedness. In the section "Toward the World" (111–62), the memoirist collects the chapters that deal with her body's change in directionality in the social world, from the inward direction of the private experience of pain to the outward behavioral expression of suffering.

The cartography of Berger's pain and disability is outlined by the contact of the disabled or ill body with other bodies in the social world, and more specifically by the contact of the eyes of the able-bodied and the body of the ill and disabled. This

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phenomenon can be explained with Ahmed's reference to Franz Fanon's idea of the black body as the object of the white gaze. Similarly to the racializing power of the white gaze, the able-bodied gaze points to bodily difference (functional and/or esthetic). In the chapter "Fourteen Ways of Looking at the Horizontal Woman (after Wallace Stevens)" (120–132), Berger explores the impact of the gaze on her embodied experience by alluding to Stevens' poem "Thirteen Ways of Looking at a Blackbird." Unlike Stevens' blackbird, the horizontal woman is aware of being looked at by others, and this is reflected in the narrative strategy adopted by Berger, as she recalls her experience in fourteen social spaces over ten years using the third person. This perspective can be interpreted as the narrativization of what Leder calls "social dys-appearance," or the incorporation of "an alien gaze, away, apart, asunder, from one's own, which provokes an explicit thematization of the body" (*The Absent Body* 99). Berger's dissociation of her narrative voice from her horizontal self reflects her intention of presenting the contraposition between the two dimensions of the act of looking from an oblique angle. The narrator adopts a queer perspective to reveal that the gaze is an instrument of violence against non-normative bodies. She pays close attention to the setting, the context, and the source of the gaze and the attitude and intention of the upright subjects regarding the horizontal woman.

In the same way that "race is an effect of racialization" as Ahmed argues (112), disability can be also defined as a construction. In fact, according to Shuttleworth and Kasnitz, disability is "the negative social response or social exclusion that may come into play because of perceived impairments" (330). Berger further explains that to be disabled above all implies the social construction of the disabled subject as the "other" by the able-bodied:

1 Without a common language for sharing the deepest experiences of the self,
2 isolated with a “subterranean fact,” the person in chronic pain, or the person
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4 painfully disabled, can feel like an immigrant in a new world, on real terra
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6 infirma. Horizontal, I began to operate like a stranger in the world, uneasy,
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8 too willing to please, trying too hard to blend in, though everyone was
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10 looking down on me. We could have been two species: those who move
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12 around and those who lie down. They were the natives, I the intruder. (51)
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21 Referring back to Scarry’s work, Berger explains that the problem of intersubjectivity
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23 caused by pain is not simply linguistic, but also cultural. The worlds of illness and
24
25 health are the product of both the lived experience and collective discourses.
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27 As Ahmed claims, bodies come together in groups when they are
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29 going in the same direction: “a ‘we’ emerges as an effect of a
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31 shared direction toward an object” (117). The “we” becomes the dominant group when
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33 it establishes the directionality toward objects in an exclusionary way. As a chronically
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35 ill subject, Berger presents illness from the perspective of the “other,” a queer body,
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37 emphasizing a dual feeling of displacement. On the one hand, she *feels* like a foreigner
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39 in the world of illness, away from the familiar world she inhabited before the accident.
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41 On the other, she is *seen* as a stranger in the world of health, since her presence in the
42
43 public world disturbs the “given” order of things. Berger captures the disorientation she
44
45 experiences in both worlds in the chapter “The Phantom of Compassion: A Fairy-Tale
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47 Mélange” (149–59), a blending of allegory and fantasy about the quest of Summerlie
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49 (the horizontal woman) and Lady Abundance (her friend) in the public world, where
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51 they are marginalized by the able-bodied and pushed into exile.
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The lack of accessibility of the disabled body in the public realm, as Berger narrates, reflects the same discursive practices of colonialism, which marginalize and exclude the “other” to reaffirm the normalcy of the dominant group. As Ahmed emphasizes, this process of losing one’s place in the world is violent (160). For Berger, this violence is generated in the eyes of those who are upright, a feeling that results in the stigmatization of the disabled body: “Being stared at somehow creates a sense of shame, as though the soul suddenly assumes a face and must hide it, turning away wordless, cast off” (134). In the same way that Berger is regarded as violating the world of the abled with her horizontal position in a space that is predominantly vertical, she experiences the gaze of the abled subjects upon her body as a violation of her public self, as she inwardly pleads at a restaurant: “*Please, I am asking you, do not violate me*” (134). In this dialectical and visual process, the geographies of the other and the dominant community are produced simultaneously, since these two categories are interdependent and mutually defined in terms of oppositions. Othering implies the establishment of a hierarchy in which the dominant group beholds the discourse of health, while the inferior individuals embody the alterity, which Berger symbolizes in the correlation between her physical posture and social status:

From this angle on the floor, I look upward to people looking down on me, see the crescents of fat under chins, observe the vulnerable place where socks do not quite meet pant cuffs. Strangers try not to stare, to hold at bay their animal instinct to flee the weak or the injured. (36)

The memoirist contrasts the able-bodied person’s ordinary feeling of being observed and the impact of the gaze upon her disabled body. She is seen by others as a devalued

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body, a view that responds to the categorization of the subject's behavior and abilities according to specific social standards and norms.

The land of illness or "terra infirma" becomes the other side of the world, or as Sontag argues "the night-side of life" (3). Again, the distance between the land of illness and the land of health is not physical, but ideological. While health is what is "here," "a line from which the world unfolds," as Ahmed explains in the case of whiteness (121), illness is what is "there," everything that is not identified with the normative values of health and is pushed to the margins. The ill body embodies this distance from the world of health. The positionality of the ill body in the world is crucial to determine how the subjects locate themselves "here" or "there." Subjects, however, are not merely situated in the world. They are conscious of their situation or, as Ramsey Eric Ramsey put it in *The Long Path to Nearness*, they are "a-where," referring to "the simultaneous recognition that agents always find themselves being some-where" (130). The contact of bodies in the social world implies the awareness of their positionality. Therefore, when Berger interacts with able-bodied subjects, she is aw(h)ere of her positionality in the land of illness and her displacement in the land of health, something that she expresses by defining herself as the "other": "Becoming Other, I could partly experience the reverberations of physical, emotional, and ethnic difference perceived as oddness in our culture, which favors the usual and the robust" (1996, xvii).

Experiencing space from a queer angle, as Berger does, reveals that the world is more accessible for certain bodies, forcing those who do not belong to the dominant group to see themselves not as natives, but as the "other," as immigrants in their own homeland. Disability, consequently, is not exclusively related to Berger's physical condition, but to the cultural constructions that map disabled subjects out of the public

1 world. Lack of accessibility, therefore, is contingent to architectural barriers, as well as
2 direct and indirect forms of political, social or legal discrimination and oppression.
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6 **Conclusions: Toward the world, toward possibility**

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9 Berger's memoir contributes to disorienting the taken-for-granted notion of body as the
10 product of sociocultural and biomedical discourses. She unveils a world exclusively
11 constructed by and for healthy and abled bodies. In this ableist world, the unbalanced
12 and horizontal body feels vulnerable, not only due to physical damage, but also due to
13 social stigmatization. As Ahmed puts it, queer bodies are "stopped" in their attempt to
14 act in the world (139). Berger's intentionality is not only blocked by pain, which in its
15 centripetal mode restricts her mobility, but also by the gaze of the upright subjects.
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25 Reorientation in the public world is not possible for Berger, since her body is constantly
26 observed by the disembodied ableist gaze. This feeling of displacement is not only
27 experienced outdoors; the domestic space for Berger is equally unfamiliar in her
28 horizontal position. Berger's world—that is, the usable space for her body—is restricted
29 not to domesticity, but to a few rooms or areas of her house where she can perform her
30 ill-related work. Pain shrinks her world, often to the size of her sickbed.
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41 Additionally, the extension of this dislocation to the dismantlement of the family
42 structure and her own identity due to dependency reinforces the multidimensionality of
43 the concept of orientation beyond its spatial connotations to consider the ill subject's
44 experience of lostness, isolation, and estrangement. The phenomenological approach
45 applied in this article aimed to provide a deeper understanding of the subjective
46 experience of illness through autobiographical storytelling. This type of narrative offers
47 a new lens through which to explore experiences of non-normative orientations. The
48 teller makes an effort to explain what it means to be ill, and this implies starting upon a
49 personal quest for meaning, as Berger does to reorient her disrupted biography.
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Although the quest narrative formula is sequential, chronic illness deprives Berger's story of a clear direction and destination. The open ending of her account only points to the fact that orientation is a never-ending process and that the end of the story about chronic illness embraces possibility. The lack of a narrative conclusion can be also interpreted as a strategy to disorient readers, who often expect a decisive closure to illness and disability that precedes the writer's reorientation to "normal" life. An open ending suggests the integration of dysfunction into the narrator's identity, as she takes illness and disability as the starting point of her new life in the vertical world. In the last chapter of her memoir, after recovering some motor functions but uncertain about her future, Berger asserts that she keeps moving forward in the world: "I take step after step into a new world, wild and joyous and fearful with possibility" (216). Despite the restriction of her sense of "I can" imposed by illness and disability, Berger is able to conceive new possibilities to participate in the vertical world, redefining her recovering body as the core of potential action.

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Acknowledgements: This work was supported by the Spanish National Research Programme under Grant PID2019-109565RB-I00, and the Government of the Principality of Asturias under the programme "Severo Ochoa para la formación en investigación y docencia."

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