



## "Je ne sais plus du tout qui je suis": The Phenomenology of Cancer in Anne Cuneo's 'Une cuillerée de bleu'

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“Je ne sais plus du tout qui je suis”:

The Phenomenology of Cancer in Anne Cuneo’s *Une cuillerée de bleu*

Steven Wilson and Sylvia Hübel

AS MEDICAL PHILOSOPHER KAY TOOMBS has noted, modern clinical practice has, by convention, conceived of the body in mechanistic terms, implicitly emphasizing its debts to the Cartesian principle of the fundamental split between mind and body: “The traditional biomedical paradigm focuses exclusively on the body-as-machine, with a concurrent de-emphasis on the personhood of the patient and the reality and importance of the human experience of illness.”<sup>1</sup> Georges Canguilhem, having traced the influence of Descartes’s dualistic archetype of embodiment back to the work of nineteenth-century physiologist Claude Bernard and sociologist Auguste Comte, is credited with being the first philosopher “who refutes in a convincing manner the biostatistical disease concept.”<sup>2</sup> Championed by Christopher Boorse in the 1970s, this concept treated human beings as machines, and illness as the malfunctioning of bodily parts. Canguilhem developed instead “a view according to which health should be approached as an evaluative concept studied at the level of personal, clinical experience” (Svenaeus 67). A focus on subjectivity is particularly significant if we accept that, for the patient, illness is experienced first and foremost as “a disruption of [the] *lived body*” (Toombs 214), an interruption of the structures and patterns of everyday life, strained relationships within social and family networks, and altered perceptions of the world. Given that serious illness is usually unforeseen, and its diagnosis accompanied by feelings of shock, anxiety, and disbelief, health sociologist Michael Bury has characterised chronic forms of illness in particular as a “biographical disruption,” arguing that they interfere not only with our

general wellbeing but also with our identity, relationships, social life, and activities.<sup>3</sup> By tracing the nature and production of knowledge to a subjective understanding of “the body,” this article will seek to shed light on the embodied experience of disease by adopting a phenomenological approach to the study of illness. It takes as its case study a relatively recent cancer autopathography, Anne Cuneo’s *Une cuillerée de bleu* (1979). Supported by a reading of the connection between meaning and the “lived body,” as theorised by French phenomenologist Maurice Merleau-Ponty, the article will consider how the experience of illness affects how the patient perceives her body, self, and world. It will propose that, in the case of Cuneo, who survived her cancer, autopathography gives expression to the subjective realities of illness and suffering as experienced by the perceiving body. In the course of our analysis, we will engage with the following overarching questions: if, as Schultz asserts, autopathographies are “phenomenological constructs,” in which “the compulsion to tell [...] foreground[s] patients’ perceptions of altered body images and physiological processes,” what is the value of using phenomenology as a theory to be applied to autopathographical texts, and how can autopathography help us to illuminate phenomenological ideas?<sup>4</sup>

### **Phenomenology: body as medium of perception**

Susan Sontag famously distinguishes between the “kingdom of the well” and the “kingdom of the sick” in her seminal essay *Illness as Metaphor*, stating that every human being holds “dual citizenship” and travels between these “kingdoms” as citizens of one or the other.<sup>5</sup> Rejecting the binary of health versus illness, Havi Carel proposes that we should regard the two “kingdoms” of health and illness as connected rather than separate entities, suggesting that one of the certainties of human life is that we will enact a series of transitions from one “kingdom” to the other: “[We] require a shift in the way we think about health and illness. We need to move from seeing them as mutually exclusive opposites, towards a continuum or blend of the

two, allowing for health within illness in people who are objectively ill.”<sup>6</sup> Carel’s argument for a change in perspective in how we approach health and illness serves as the premise for an injunction for a more fundamental break from the use of binary paradigms in medicine:

A second shift is required, away from an objective deficit-centred health assessment towards giving more weight to subjective first-person reports or to lived experience. Both shifts are achieved by moving from a purely naturalistic view of health and illness to one that incorporates phenomenological insights. (Carel, *Illness* 93)

In recent years, medical philosophers have made the case for a new conception of illness that stems from the principle that biological body and personhood are inextricably linked. This “alternative paradigm,” which “unites body and mind (or body and self) and situates body in the midst of the environing world,” encourages us to understand illness “not simply as the physical dysfunction of the mechanistic body, but as the disorder of body, self and world” (Toombs 202). A move away from a focus on physical facts – that is, an “objective (and objectifying), neutral and third-personal” view of illness which Carel labels the “naturalist” approach – and towards a conception of illness that takes account of lived experience, be it physical, psychological or social, invites us to consider illness through the lens of phenomenology (Carel, *Illness* 9-10).

Eschewing an approach that centres on the physiological, phenomenology – “the science (*logos*) of relating consciousness to *phenomena* (things as they appear to us) rather than to *pragmata* (things as they are)” – offers a methodology that is particularly advantageous for an examination of illness.<sup>7</sup> As Toombs writes, “Illness is experienced by the patient not so much as a specific breakdown in the mechanical functioning of the biological body, but more fundamentally as a disintegration of his ‘world’” (Toombs 207). In other words, illness is not

only an obstruction to health but also a phenomenon the patient lives through – one that disrupts the everyday experiences and interactions that give meaning and identity to the self. Privileging an analysis of first-person experience, phenomenology, as its founder Edmund Husserl put it, requires us to go back to “the things themselves,” in this case, the patient suffering from disease.<sup>8</sup> This is not to say that a phenomenological approach to illness should supplant a naturalist one; rather, it allows us to complement specialist attention to biological dysfunction with an appreciation of the disruption this causes to the lived experience of the socially-embedded human being, affording us a more complete understanding of patienthood, illness, and well-being. Thus, whereas Sontag declares that the aim of her analysis is not to describe “what it’s really like to emigrate to the kingdom of the ill and to live there” (Sontag 3), but rather to deal with some of the myths and superstitions that society and culture have constructed to describe illnesses such as tuberculosis and cancer, this article proposes to approach Cuneo’s autopathography from precisely the opposite direction, and to consider “what it’s really like” to be a cancer patient.

Written between May 18 and November 10, 1978, and published the following year, Anne Cuneo’s breast cancer autopathography, *Une cuillerée de bleu*, subtitled “chronique d’une ablation,” is more than an autobiographical account of patienthood and pain. While it recounts medical visits, treatments – including chemotherapy – and a deep sense of suffering, it enjoys the privileged status of being recognized both for its literary merit and its use as a patient resource.<sup>9</sup> Having survived her cancer, Cuneo informs us that “Des médecins ont donné le texte à leurs patients, pour les encourager à résister à la maladie, à se défendre. Il a été distribué dans les hôpitaux.”<sup>10</sup> In spite of the fact that the text has been judged of value for patients enduring treatment for cancer, there has been a distinct paucity of critical focus on Cuneo’s autopathography until now. Isabelle Favre, almost alone in having devoted any significant attention to the text, examines the questions it raises in respect to the “rapports entre

la psyché et le corps.”<sup>11</sup> Noting that Cuneo’s bodily experience shapes her written account – “l’écriture passe par le corps pour signifier” (Favre 250) – Favre traces the use of metaphorical, ideological, and mythical language in Cuneo’s account to a discernable sense of bodily alienation: “Avec *Une cuillerée de bleu*, on aborde l’analyse de la relation de l’individu à son corps qui lui échappe; la marginalisation débute par une aliénation de soi à soi, et se poursuivra par un sentiment de mise à l’écart, de distanciation du corps individuel au corps social” (Favre 245). In turn, Favre argues that Cuneo “développe [...] des stratégies textuelles qui l’aident à faire face à un coefficient d’adversité qui [...] n’a rien de mythique” (Favre 252). By way of contrast, our analysis does not focus on Cuneo’s “textual strategies” for confronting cancer; rather, it examines the ways in which her writing communicates a sense of the lived experience of cancer. A brief discussion of the links between phenomenology, illness, and the perceiving body will provide a conceptual framework for doing so.

As Martin Heidegger proposes in his phenomenology of the everyday in *Sein und Zeit* (1927), human experience is informed by a sense of *in-der-Welt-sein* (*being-in-the-world*): as this use of hyphens suggests, the self is to be regarded as imbricated in the world instead of existing in a subject/object relationship with it. While we experience our bodies, we also live through them, connecting to the environment around us in a synthesis that suggests the body is not, as Cartesian dualism would have it, merely something we inhabit. Merleau-Ponty also rejects a reductionist view of the body solely as physical entity – what he calls *le corps objectif* – in favour of a more complete understanding of the experience of the lived body – *le corps propre*.<sup>12</sup> Articulating the unity of mind and body, Merleau-Ponty asserts that subjectivity is founded on the perceptual experience and sensual knowledge that are generated by interaction with the lived environment, stating, “le monde est non pas ce que je pense, mais ce que je vis” (*Phénoménologie* xii). Merleau-Ponty’s phenomenology therefore “understands consciousness as not only embodied but also socially and existentially situated” (Carel, “Phenomenology as

a Resource for Patients” 100). The body “understands” and actively “inhabits” the world; it is the means by which, through the senses, we perceive the world.<sup>13</sup> In Merleau-Ponty’s own words:

Je suis donc mon corps, au moins dans toute la mesure où j’ai un acquis et réciproquement mon corps est comme un sujet naturel, comme une esquisse provisoire de mon être total. Ainsi l’expérience du corps propre s’oppose au mouvement réflexif qui dégage l’objet du sujet et le sujet de l’objet, et qui ne nous donne que la pensée du corps ou le corps en idée et non pas l’expérience du corps ou le corps en réalité.  
(*Phénoménologie* 231)

If the body is neither truly subject nor object, the direct experience of the body is neither merely objective nor purely perceptual and subjective.<sup>14</sup> Every experience involves our body as well as our mind; it is therefore never possible to divorce the materiality of the world from our existential condition, a principle that Merleau-Ponty frames using the concept of “intertwining” to describe the inseparability of the subject/self from the world.<sup>15</sup> In so doing, he reclaims lived bodily experience as a source of knowledge, emphasizing that people make sense of the world through their bodies. As Toombs puts it, echoing some of the language used by Merleau-Ponty, “I am ‘embodied’ in the sense not that I ‘possess’ a body but in the sense that I *AM* my body. Rather than being an object *of* the world, my body is my particular point of view *on* the world” (Toombs 202).

While the approaches of a range of phenomenologists from Husserl onwards lend themselves to a description of the embodied experience of illness, in which a writer such as Cuneo seeks to raise the question of the meaning of being ill, a state that in turn affects the phenomenal world – the life-world – of the individual, it is Merleau-Ponty’s emphasis on the

importance of perception that commends his work as a particularly instructive intertext in an analysis of the modern cancer autopathography.<sup>16</sup> As illness disrupts the patient's sense of being in the world, body and perception react, affecting movement, ability, and human existence as a whole. Mobility, which Merleau-Ponty construes as basic intentionality, thus becomes restricted, and one's being in the world is inhibited as a consequence: "La conscience est l'être à la chose par l'intermédiaire du corps. [...] [M]ouvoir son corps c'est viser à travers lui les choses" (*Phénoménologie* 161). As mobility is connected to Merleau-Ponty's concept of the intentional arc, by which our relationship with the world is made up of time, environment and intentionality, and the body mediates our experience of the world, when a disease inflicts the body, illness manifests itself in its disruption to selfhood as well as bodily function: "C'est cet arc intentionnel qui fait l'unité des sens, celle des sens et de l'intelligence, celle de la sensibilité et de la motricité. C'est lui qui se 'détend' dans la maladie" (*Phénoménologie* 158). From a phenomenological point of view, illness is therefore not to be regarded as the result of bodily invasion by a reified organism; instead, as it becomes perceptibly embedded into one's being, illness may be conceptualized as a "complete form of existence" (Merleau-Ponty, *Phenomenology* 123). While the nature of illness is indeed existential, changing the shape of life for the sufferer, it is important to appreciate each patient's individual experience of illness. Acknowledging that illness manifests itself in a variety of guises and experiences, phenomenologists have nonetheless grouped these into broad categories, including a consciousness of the body as alien "other," and a subsequent dissolution in the unity of the "lived body"; a divorce between body and self, provoked by an objectification of the body (often as a result of the intervention of medical authority); and a sense of unfamiliarity with the world and insecurity in social relationships. These will now be considered in the context of Cuneo's cancer autopathography.



### **Disruption, alienation, fragmentation**

Referring to a tiny amount of color that, when added to an artist's palette, gives nuance, encourages a new perspective, and puts in place the conditions allowing for a reappraisal of a work-in-progress, the title of Cuneo's autopathography is symbolic. In *Une cuillerée de bleu*, language communicates more than the corporeal dimension to illness; Cuneo's cancer – "cette cuillerée de bleu en moi" (13) – is regarded as an invitation to reflect on broader questions concerning the sufferer's life, identity, and fate. The three definitions of the keyword in the text's subtitle, "ablation," are to be considered in this context. Taken from the *Robert* dictionary, each serves as an epigraph to a section of the narrative: "Action d'enlever. Pratiquer l'ablation d'un rein"; "Perte de substance subie par un relief, pour quelque cause que ce soit. L'érosion est une sorte d'ablation"; "Perte de glace d'un glacier." This attentiveness from the very beginning of Cuneo's account to the expressive power of language, both literal and metaphoric, announces an intention not only to focus on the physicality of bodily alteration, but also to pose some thought-provoking questions with respect to what it *feels like* to be a "cancéreuse." In *The Illness Experience*, Morse and Johnson distinguish between four stages in the experience of severe ailments and disorders.<sup>17</sup> In the uncertainty period, when patients first discover their symptoms, they begin to lose faith in their bodily functionality. Following this, in the disruption stage, they face up to the need to relinquish control over themselves to healthcare providers, before seeking meaning and "striving to regain themselves" (Morse and Johnson 321). During the final stage, they attempt to retake control of their lives in a bid for recovery and closure. Even though Cuneo's narrative makes reference to all the elements of this illness model, it aligns itself most closely with the disruption stage.

While Cuneo's autopathography deals with several months of her life after diagnosis and mastectomy, it does not follow a chronological order, with the result that it draws attention to the sense of incoherence and chaos produced by breast cancer. This chaotic order manifests

itself in her writing through a series of reflections on her shifting relationship with her body and, as a result, an unclear sense of her identity: “À partir du jour où tout a commencé, mon château est devenu sable que les flots peuvent à tout instant emporter” (70). As the metaphor of the sandcastle suggests, from the moment she enters the diagnostic process, Cuneo appreciates that all sense of security in her life is shattered. Recognizing that “C’est [l’incertitude] qui m’angoisse si fort, parfois” (9), and that “Le terrible de cette merde, c’est de ne pas savoir. Ne pas savoir si le cancer existe encore en moi ou non” (123), Cuneo takes cognizance of her loss of control over her body. The framing of cancer as an objectified entity living in the body causes her relationship with her body to undergo a subtle shift. This shift is emphasized in the use of demonstrative adjectives when referring to bodily parts – for example, “cet uterus” (117) – or, more generally, when she writes of “Ce corps sans sein auquel je n’ose penser” (90). This formal technique draws attention to Cuneo’s unstable and problematic relationship with the idea of the “lived body” she has known and experienced until now; the result is that she places distances between her self and her body: “Ce corps que les siècles ont façonné, ce corps dont ma mère a accouché, ce corps que j’ai nourri, animé – ce corps dans lequel je me suis blottie comment, aujourd’hui, le préserver? Muet et bruyant, il se manifeste à moi dans une douleur assourdissante” (69).

Cuneo’s subsequent mastectomy, which she experiences as a violation of corporeal boundaries and a reshaping of her body, affects her sense of physical integrity: describing herself as a “prisonnière d’une carcasse que je ne contrôle pas,” she writes of waiting for the consultant gynaecologist to arrive and tell her “où sont mes frontières” (110). This sense of alienation, bodily disunity, and uncertain identity caused by her treatment is reflected in the duality Cuneo perceives between her diseased body and her healthy mind: “Dans le taxi, mon cerveau continue à fonctionner dans une direction et mon corps dans l’autre” (113). This experience fits with ethicist Margaret Farley’s argument that we are all “natural dualists,”

unaware of our bodies until they cease to function ‘normally.’ Through pleasure or pain, Farley argues, we adopt a dualistic stance, whereby we consciously distance ourselves from what we perceive as our failing body.<sup>18</sup> In *Une cuillerée de bleu*, this distancing is revealed when Cuneo recalls feeling alienated from her body: “C’est cette impression d’être peu à peu dépouillée de mon corps, dépossédée de tout mon destin, de mon temps” (117). This response, in turn, provokes a crisis in her experience as an embodied self, her pain-ridden body alienating her from her familiar world and other people: “Je pose sur le monde un œil différent, complètement détaché: je vais mourir, il n’y a plus de place en moi pour la peur de vivre” (97).

Cuneo’s approach to her body reminds us that the concept of the embodied subject is central to autopathography, as only first-person knowledge can inform us about what it is like to inhabit a body during illness and medical treatments. Autopathographies, particularly those that privilege a phenomenological description of individual experience, thus have the potential to reveal much more about the experience of illness than sociological, scientific or medical narratives on their own. As Cuneo begins to contemplate the disintegration of her body caused by a mastectomy, and its subsequent effects on her sense of identity, entries in her autopathography appropriate a discourse of fragmentation: she thinks of herself as a “moi mutilée” (21) and states that she would prefer “plutôt la mort que cette mutilation” (23). The vociferous quality of the language used to describe the fears she experiences concerning the fragmentation of her body corresponds to a heightened sensitivity to the effects of treatment on her sense of gender identity in particular. Cuneo experiences her mastectomy as an attack on her feminine self, insisting the removal of corporeal signs of femininity and female sexuality will render her incomplete: “C’est la condamnation à mort de ma vie de femme que vous prononcez là. [...] Qu’on m’enlève ce sein, et je n’existerai plus” (22). Her experience of breast cancer is arguably-felt most profoundly in the fear that she will lose the affection of her partner, Eric: “Quand on m’aura enlevé un sein, je ne serai plus une femme. Comment va-t-il encore

m’aimer? Cette souffrance-là par-dessus l’autre” (32). Cuneo makes this point repeatedly in her autopathography, revealing that the fragmentation of a supportive relationship – articulated in the narrative fragmentation of the text, the framing of “je” and “lui” in opposition to each other, and the posing of open questions – troubles her more than bodily dismemberment per se:

Il marche vers la porte.

Je le regarde.

Je l’aime.

Et lui, comment m’aimera-t-il, à demi mutilée?

Sans identité?

[...] À la porte, il se tourne, il me regarde, il me sourit.

Des yeux, j’essaie de l’imprimer en moi. Mon amour.

Il me quittera.

Je serai seule.

Au secours. (42)

### **Medicalization and objectification: resistance and repair**

*Une cuillerée de bleu* offers an insight into the process through which medical authority takes control of the patient’s body and life, in line with medical sociologist Arthur Frank’s description of medical interventions as a form of colonization, whereby doctors claim the body of the patient as their “territory” and assume power over them.<sup>19</sup> From the moment of hospitalization, Cuneo, subjected to what Foucault refers to in *Naissance de la clinique* as the “medical gaze” (“Œil qui sait et qui décide, œil qui régit”),<sup>20</sup> as well as the physical touching and prodding of healthcare providers, relinquishes her privacy and control of her intimate

bodily space, causing feelings of depersonalization and objectification. When she presents for her first medical appointment, Cuneo feels anatomized and thinks of her body as a site of diagnostic and treatment interventions: “On me lave. On refait mon lit. On emmène la transfusion et la perfusion. On me lève. On me soutient jusqu’aux toilettes” (57). The language used in this quotation to describe the asymmetry of the doctor-patient relationship draws attention to the limited autonomy of the patient subordinated to the control of medical practice. Medical authority is rendered in the anonymous subject pronoun “on” – the active agent each time – while the passive patient, reduced to her ill-functioning body parts, linguistically inhabits the place of the object pronoun. Through its emphasis on the objectifying stance and discourse of medicine, Cuneo’s autoethnography contests the practice of “medicalization” by relating an abundance of specialist medical terms such as “transfusion” and “perfusion” used to describe her condition, as well as the ways in which she feels that she is compelled to submit her body to medical authority.<sup>21</sup> Yet Cuneo’s reflections on the power dynamic in doctor-patient interactions prompt an important change in her approach to medical discussions about her body. A few months before diagnosis, when she seeks medical help because of some suspicious symptoms, her personal knowledge of her body and its functioning is dismissed by the doctor. This event triggers feelings of anger, frustration, as well as objectification in her: “La gynécologue m’a dit que mon sein droit était normal. Elle est médecin, donc elle le sait. Merde! C’est MOI qui savais. Moi. Sur une intuition qu’aucune pensée rationnelle ne pouvait justifier (je n’avais même pas mal)” (126). The tension between personal and medical knowledge manifested in this quotation, and the rhetorical and stylistic rendering of the narrative – through the effects of repetition, capitalisation, and the use of irony – testify to an unwillingness to permit experiential testimony to be usurped by the voice of supposed medical expertise.

Although Cuneo records not being taken seriously as a knowing subject and, by

extension, as a valid source of knowledge, she is nonetheless keenly aware of her epistemological relationship with her body and her possession of knowledge that medical staff do not hold. Indeed, at one point she writes of her guilt about failing her body because she ignored warning signs communicated through dreams and bodily “intuition”:

Ces rêves prémonitoires, ces intuitions qui m’ont fait pressentir à certains instants l’évidence même, je les ai niés car ils venaient d’ailleurs que du pur raisonnement. Ma nature ‘suiveuse’ m’a poussée à me fier au seul domaine qui ait droit de cité dans cette société: celui de la raison pragmatique. (135)

As a consequence, Cuneo turns away from her earlier identification with positivist thinking and rationality, and she begins to place more faith in bodily knowledge based on feelings and intuitions. She rejects the dichotomy between her intellect and emotions, between medical evidence and her subjective bodily knowledge; instead, she pays attention to the sensations of her body and the messages of her subconscious, attentive to the fact that bodily awareness and experience in themselves constitute forms of knowledge. The value Cuneo places on the body as a medium of perception is significant in three respects: it situates her narrative production within the conceptual parameters of phenomenology, particularly Merleau-Ponty’s suggestion that the body functions as a medium of perception; it allows her to challenge expressions of medical authority that do not take sufficient account of bodily experience; and it echoes feminist critiques – espoused, for example, by Schultz – that argue that medical practice often patronizes female patients in particular by overriding with expert knowledge their tendency to offer experiential accounts. Within this context, it is apposite to note that Cuneo records on one occasion the sense of empowerment that comes when one particular doctor – a woman – takes the time to listen to her experience and involve her in the decision-making process, treating her

as an equal and respecting her subjectivity: “Elle réussit à me donner la sensation que je suis une partenaire, et non une victime totale. Elle est la première, d’ailleurs, à me parler d’adulte à adulte, à me dire les choses clairement” (88). This observation is symptomatic of a yearning that is evident throughout *Une cuillerée de bleu* for a holistic and patient-centered approach to the treatment of illness.

Before the advent of advanced medical technology, patients’ personal reports represented the primary source of information enabling doctors to make a diagnosis. However, with the development of medical sciences, the voices of the physician and patient were placed in opposition to each other, which established dichotomies between objectivity and subjectivity, and relevant and irrelevant knowledge. Cuneo’s reflections serve as a reminder that autopathography has the potential to challenge the authoritarian, patriarchal assumptions that govern the patient-doctor relationship. As Frank has argued, autopathographies are not just stories about illness; they are also told *through* wounded bodies, including the voice. Whereas “medicine takes away voice,” autopathographies release the patient’s voice from professional medical containment, so that “telling stories of illness is the attempt, instigated by the body’s disease, to give a voice to an experience that medicine cannot describe” (Frank 7, 18). Corroborating Frank’s assertion that storytelling is an empowering vehicle in which patients’ bodies “give their stories their particular shape and direction” (Frank 27), Cuneo notes that it is through the act of writing that she is able to forge a creative path towards regaining agency:

Les cloches de midi au clocher carillonnent que j’ai raison. Que si la parole est mon salut, si l’écriture est ma plénitude, il faut parler, écrire.

Aimer et écrire. Écrire et militer. Militer et aimer.

Aimer en militant et en écrivant.

Voilà mes axes vitaux. (25-26)

The parallels Cuneo establishes between the verbs “écrire” and “militer” in this quotation evoke Avrahami’s argument that “the felt tension between empowerment and powerlessness points to the invasion of the text by the sick body.”<sup>22</sup> Unlike the traditional use of “battle metaphors” in modern cancer narratives, the use of military discourse in Cuneo’s autopathography suggests that she regards her text as a site for resistance on which the lived body negotiates with medical power, through the act of writing, in a bid to restore the subjectivity – and thus the voice – of the patient. In this way, *Une cuillerée de bleu* exemplifies Foucault’s notion of the genealogy of power relations in a medical context, encapsulated in his now famous remark “Là où il y a pouvoir, il y a résistance.”<sup>23</sup> Cuneo’s “resistance” is evident in the strident tone of some sections of her autopathography, including the following excerpt in which her “moi nouveau” is positioned in contradistinction to the medical “il,” and the emphatic pronoun “toi” is placed in opposition to “les autres [médecins]”:

Ce moi nouveau, récemment accouché, qui criait il y a quelques semaines: “Je serai celle-ci ou je ne serai plus,” ce moi nouveau se dresse malgré l’interdit. Il dit *non*. Finis les silences. Finies les larmes qu’on ravale. Tu hurleras en plein jour. Les autres s’intéresseront à tes cris ou non – ce n’est pas ton problème, c’est le leur. Toi, tu dois vomir ta vie de muette jusqu’à la dernière cellule pourrie. (24)

For all the sense of fragmentation and struggle that characterizes Cuneo’s autopathography, the writing process, which tells of her shifting relationship with her body and her broken connections to the world, allows her to translate her experience of cancer into words. Cuneo thereby manages to forge new connections to new worlds by entering into dialogue with her body of readers. Relating the experience of what it is to be a cancer patient, in a postface to her



autopathography dated April 2004, she recounts having received “des centaines de lettres” from both male and female cancer patients declaring that her inspirational combative attitude “leur avai[t] sauvé la vie” (169). As Frank suggests, “as wounded, people may be cared for, but as storytellers, they care for others” (Frank xii). Nonetheless, by telling the story of her illness and reclaiming her embodied experience through the writing process, Cuneo is also searching for meaning, a quest that enables her to reestablish herself as a knowing female subject with epistemological, moral, and political agency. The act of writing an autopathography may therefore be seen as playing a significant role in the reconstruction of Cuneo’s post-mastectomy identity; as such, *Une cuillerée de bleu* might also be read within the conceptual framework of the idea of “narrative repair.” As Hilde Lindemann Nelson has persuasively argued, if identities can be “narratively constituted” and “narratively injured,” they can also be “narratively repaired” in the sense that the writing process provides the potential to enable the author to construct a new self.<sup>24</sup> Cuneo’s emotional dedication to writing about her experiences – “La rage remonte. Et avec la rage l’écriture. Une fois la peur surmontée, d’ailleurs, les mots se pressent. Ça sort comme un vomissement” (40) – provides not simply an outlet, but also a constructive framework in which she can regain an agency that has been ignored or misrepresented by the dominance of medical culture, and renegotiate medicine’s discursive management of her illness. Writing, for Cuneo, thus represents more than an attempt to understand her experience of cancer; in the zeal with which she writes, a new identity as patient-writer is affirmed: “Je ne laisserai pas s’arrêter maintenant cette plume trempée de sang et perclue de douleurs. Mon moi le plus authentique est-il un moi écrivain?” (70). The construction of a narrative supports the cognitive restructuring of Cuneo’s lived reality, allowing her to integrate her experience of illness into a newly constructed identity.<sup>25</sup>

### **Conclusion: autopathography as phenomenology**

*Une cuillerée de bleu* gives us a perceptive insight into the life-world of a cancer patient. Exploring questions of bodily alienation and fragmentation, as well as the passivity of patienthood, all of which result from the experience of illness, a reading of Cuneo's autopathography through the lens of phenomenology reminds us that the suffering subject – dehumanized by an objectification that characterizes the clinical encounter – perceives illness first and foremost in terms of the disruption caused to the lived body. While the physician may approach illness as a biological dysfunction requiring medical intervention, Cuneo expresses in blunt, existential terms her difficulty in coming to terms with the physical, psychological, and emotional realities of illness: “Je souffre affreusement. Je ne sais plus du tout qui je suis” (139). Through its phenomenological depiction of embodied experience, Cuneo's autopathography offers a rich contribution to the understanding of what it is to be a cancer patient. Furthermore, given that it paints a picture of a patient who actively resists the power of medical authority, it also contributes to the cultural paradigm shift that has seen patients change in recent years from passive figures and recipients of care to active agents communicating and offering embodied knowledge within the framework of “patient-centred care.” In *Une cuillerée de bleu*, we witness the rise of an empowered patient who promotes an understanding of the medical value of lived experience and whose first-person narrative plays its role as a patient resource in a community of sufferers, all of which helps to dismantle the taboo surrounding conversations about breast cancer.

In her autopathography, Cuneo paints an intimate portrait of the cancer patient as an embodied, relational subject, embedded in a particular life context. In this way, we should not simply read *Une cuillerée de bleu* within the critical framework of phenomenology, illuminating as that is. Instead, following Svenaeus's argument that “Phenomenology is meant to enrich our understanding of health in adding to the disease-level analysis a level of analysis that addresses the questions of how the physiological states are lived as meaningful in an

environment” (Svenaesus 105), it is apposite that we should identify *Une cuillerée de bleu* as a phenomenological text, depicting experiences in terms of the patient’s thoughts, feelings, and bodily sensations, and giving voice to the experience of living with cancer. In this way, Cuneo’s narrative also offers an outline of potential benefits of the “new model” of medicine advocated by Schwartz and Wiggins, in which the scientific rigor that is the underpinning of medical practice allies itself with an appreciation of “the primacy of the lifeworld” of the patient.<sup>26</sup> Schwartz and Wiggins argue that this new paradigm, which they term a “phenomenological model of medicine,” provides an opportunity to heal the debilitating breach that has opened up in recent decades between the medical sciences and the humanities (Schwartz and Wiggins 359). A reading of Cuneo’s cancer narrative through the lens of phenomenology affirms that autopathography, by offering an enriching understanding of the embodied experience of “what it is like” to be ill, has a pivotal role to play in this endeavor.

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*Notes*

<sup>1</sup> S. Kay Toombs, “Illness and the Paradigm of Lived Body,” *Theoretical Medicine*, 9 (1988): 201.

<sup>2</sup> Fredrik Svenaesus, *The Hermeneutics of Medicine and the Phenomenology of Health: Steps towards a Philosophy of Medical Practice* (Dordrecht: Kluwer, 2000): 67, n.107.

<sup>3</sup> Michael Bury, “Chronic Illness as Biographical Disruption,” *Sociology of Health and Illness*, 4 (1982): 167-82.

<sup>4</sup> Jane E. Schultz, “Valid/Invalid: Women’s Cancer Narratives and the Phenomenology of Bodily Alteration,” *Tulsa Studies in Women’s Literature*, 32:2 (2013): 71.

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<sup>5</sup> Susan Sontag, *Illness as Metaphor and AIDS and its Metaphors* (New York: Penguin, 1991), 3.

<sup>6</sup> Havi Carel, *Illness*, rev. ed. (2008; Durham: Acumen, 2013), 93.

<sup>7</sup> Havi Carel, “Phenomenology and its Application in Medicine,” *Theoretical Medicine and Bioethics*, 32 (2011): 34. As Carel further notes elsewhere, “a philosophical framework that views cognition as embodied, focuses on subjective experience, and provides a robust existential account of selfhood is well suited to understanding the experience of illness.” Havi Carel, “Phenomenology as a Resource for Patients,” *Journal of Medicine and Philosophy*, 37 (2012): 100.

<sup>8</sup> Cited in Svenaeus, 76.

<sup>9</sup> Cuneo was awarded the Prix Schiller in the same year as *Une cuillerée de bleu* was published, and she estimated that the text – published by French, German, and Dutch companies – ran to nearly 100,000 copies in 2004.

<sup>10</sup> Anne Cuneo, *Une cuillerée de bleu: Chronique d’une ablation* (Orbe: Bernard Campiche, 2004), 169.

<sup>11</sup> Isabelle Favre, “Francophonie Helvétique: Corps ex-centré et métonymie dans *Une cuillerée de bleu* d’Anne Cuneo,” *Romance Notes*, 38:3 (1998): 247.

<sup>12</sup> See Maurice Merleau-Ponty, *Le visible et l’invisible* (Paris: Gallimard, 1964), 313; and *Phénoménologie de la perception* (Paris: Gallimard, 1945), 235.

<sup>13</sup> Maurice Merleau-Ponty, *Phenomenology of Perception*, Colin Smith, trans. (New York: Routledge, 1962), 161-62.

<sup>14</sup> See Taylor Carman, “The Body in Husserl and Merleau-Ponty,” *Philosophical Topics*, 27 (1999): 205-26.

<sup>15</sup> Mary Rose Barral, *The Body in Interpersonal Relations: Merleau-Ponty* (Lanham MD: U P of America, 1984), 27.

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<sup>16</sup> Indeed, while Heidegger discusses dysfunctionality – or a breakdown in instrumentality – in terms of a “tool” that is “*unready-to-hand*,” with the result that the world is viewed as obtrusive or obstinate, his account does not deal explicitly with the body. Martin Heidegger, *Being and Time*, John Macquarrie and Edward Robinson, trans. (San Francisco: HarperCollins, 1962), 105.

<sup>17</sup> Janice M. Morse and Joy L. Johnson, eds., *The Illness Experience: Dimensions of Suffering* (Newbury Park CA: Sage Publications, 1991).

<sup>18</sup> Margaret A. Farley, *Just Love: A Framework for Christian Sexual Ethics* (New York: Continuum, 2006), 118-27.

<sup>19</sup> Arthur W. Frank, *The Wounded Storyteller: Body, Illness and Ethics* (Chicago: U of Chicago P, 1995), 10.

<sup>20</sup> Michel Foucault, *Naissance de la clinique* (Paris: Presses Universitaires de France, 1994), 88.

<sup>21</sup> See Peter Conrad, *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders* (Baltimore: Johns Hopkins U P, 2007).

<sup>22</sup> Einat Avrahami, *The Invading Body: Reading Illness Autobiographies* (Charlottesville: U of Virginia P, 2007), 8.

<sup>23</sup> Michel Foucault, *Histoire de la sexualité I: La volonté de savoir* (Paris: Gallimard, 1976), 125-26.

<sup>24</sup> Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair* (Ithaca: Cornell U P, 2001).

<sup>25</sup> See Anne Hunsaker Hawkins, “Pathography: Patient Narratives of Illness,” *Western Journal of Medicine*, 171 (1999): 127-29.

<sup>26</sup> Michael Alan Schwartz and Osborne Wiggins, “Science, Humanism, and the Nature of Medical Practice: A Phenomenological View,” *Perspectives in Biology and Medicine*, 28:3 (1985): 333.