

# Putting Hodgkin's lymphoma into words

Anne François's *Nu-tête*

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The sick body has been the focus of a number of narratives by contemporary francophone women writers, and several of them shared their experiences of breast cancer treatments and recovery (for example, Lydia Flem, *La Reine Alice* (2011)). There has, however, been less attention given to some other forms of cancer in francophone literature. This article thus proposes to analyse the work of lesser-known Belgian writer, Anne François (1958–2006), who wrote about Hodgkin's lymphoma. François explores this cancer and its treatment in her 1991 novel *Nu-tête* (Prix Rossel), through the character of Cécile. Although François claimed that the novel was a work of fiction, the narrative is clearly based on her own experience of the illness in 1980 and takes the reader through the various steps of the diagnosis and treatment from the perspectives of both the patient and her doctor, each using a very different language. Drawing on the works of Anne Hunsaker Hawkins, Rita Charon, and Arthur W. Frank, this article examines how this polyphonic text, written before pathographies became a more popular genre in contemporary literature, already foregrounded some of the key themes found in cancer accounts, such as the gap in discourse in the fundamental relationship between the patient and doctors and the expression of corporeal and emotional suffering induced by the illness and the medical procedures. Interestingly, the narrative also showcases the 'translation' of the patient into sets of medical images and measurements throughout their journey with illness.

**Keywords:** Anne François, Hodgkin's lymphoma, doctors, medical treatment, pathography

Nombre d'écrivaines francophones contemporaines ont dédié une partie de leurs publications au corps malade, et plusieurs d'entre elles ont partagé leurs expériences de traitements et de guérison du cancer du sein (ex. Lydia Flem, *La reine Alice* (2011)). En revanche, certaines autres formes de cancer n'ont pas fait l'objet d'une attention similaire dans la littérature francophone. Cet article propose donc d'analyser le travail d'Anne François (1958–2006), écrivaine belge peu connue, qui a écrit sur le lymphome de Hodgkin. François explore ce cancer et son traitement dans son roman *Nu-tête* (Prix Rossel), paru en 1991, à travers le personnage de Cécile. Bien que François ait affirmé que ce roman était une œuvre de fiction, le récit est clairement basé sur sa propre expérience de la maladie en 1980, dévoilant les différentes étapes du diagnostic et du traitement, tant du point de vue de la patiente que de celui de son médecin, chacun utilisant un langage très différent. En s'inspirant des travaux d'Anne Hunsaker Hawkins, de Rita Charon et d'Arthur W. Frank, cet article examine comment ce texte



polyphonique, écrit avant que les pathographies ne deviennent un genre plus populaire dans la littérature contemporaine, mettait déjà en avant certains des thèmes clés que l'on retrouve dans les récits de cancer, tels que le « décalage » de communication au sein de la relation fondamentale entre le/la patient·e et les médecins, ou l'expression de la souffrance corporelle et émotionnelle induite par la maladie et les procédures médicales. On notera aussi la façon dont le récit met en avant la « traduction » du patient en une série de résultats d'examens et d'images médicales tout au long de son parcours avec la maladie.

**Mots clés :** Anne François, le lymphome de Hodgkin, médecins, traitement médical, pathographie

The past three decades have seen the publication of an increasing number of illness narratives with many writers and artists engaging with the issues of health care and sick bodies. Among pathographies, breast cancer accounts feature prominently in works by women writers; from Susan Sontag's *Illness as Metaphor* (1978) or Anne Cuneo's *Une cuillerée de bleu* (1979) to Annie Ernaux's *L'Usage de la photo* (2005), Anne Boyer's *The Undying* (2019), and Mounia El Kotini and Maëlle Sigonneau's *Im/patiente* (2021), to name but a few. There has also been a growing number of accounts published about other forms of cancer, alongside AIDS, pathologies such as Alzheimer's disease, and epilepsy.<sup>1</sup> Narratives focusing on Hodgkin's lymphoma, whether in French or in English, are far fewer in number. Recently, Alice Baguet's 2015 graphic novel *L'Année du crabe: globules et raviolis* tackles this illness with humour, while Marine de Nicola's *Le Baiser de l'ouragan* (2017) offers a testimony of her lymphoma diagnosis and treatment. This is no doubt because Hodgkin's lymphoma is not commonly known; and for good reason since this cancer of the immune system which develops in the lymphatic system remains fairly rare.<sup>2</sup>

The book discussed in this article is Anne François' novel *Nu-tête*.<sup>3</sup> François (1958–2006), like Hodgkin's lymphoma for which both she and the novel's protagonist were treated, is not well known, despite the quality of her works. A Belgian secondary school teacher, writer, and theatre

1 See for instance Ruwen Ogien, *Mes mille et une nuits: la maladie comme drame et comme comédie* (Paris: Albin Michel, 2017); Hervé Guibert, *Le Protocole compassionnel* (Paris: Gallimard, 1991); Annie Ernaux, *Je ne suis pas sortie de nuit* (Paris: Gallimard, 1999); Caroline Vié, *Dépendance day* (Paris: Lattès, 2015); and Elodie Durand's graphic novel *La Parenthèse* (Paris: Delcourt, 2018).

2 For more information, see 'Le lymphome hodgkinien: points clés', *e-cancer.fr*, 2 June 2022 <<https://www.e-cancer.fr/Patients-et-proches/Les-cancers/Lymphome-hodgkinien/Le-lymphome-hodgkinien-points-cles>> [accessed 20 February 2023].

3 Anne François, *Nu-tête* (Paris: Albin Michel, 1991).

producer, she directed short films and TV programmes focusing both on literary and medical topics, and also organized creative writing workshops. Her two novels, published before her untimely death in 2006, focus respectively on cancer and autism, and attest to a keen interest in questions surrounding treatment and perception of medical conditions at a time when pathographies were becoming more established as a genre.<sup>4</sup> Published in 1991, and despite winning the prestigious *Prix Rossel* (considered as the Belgian equivalent of the *Goncourt*) and the *Prix NCR*, *Nu-tête* did not receive much critical attention beyond a couple of literary reviews which nonetheless praised its quality and originality.<sup>5</sup> The title and cover of the first edition of the book, both representing the head of a bald woman, are a clear reference to the hair loss experienced by the protagonist in the narrative as a result of treatment for her cancer, leaving little doubt about the novel's theme. *Nu-tête* explores various topics linked to the experience of patients in negotiating their cancer journey. The book's cover and an incipit both declare it a work of fiction, but these fail to disguise the obvious link between François and Cécile, the protagonist, who experiences the same illness as the author – and also shares her passion for dancing.

Central to illness narratives is the body, and much work on narrative medicine focuses on it, along with the voice of either the patient or the doctor and the treatment of the disease. This article discusses articulations of the body, language, and illness, in the form of a case study. It first outlines key concepts that have emerged in the field of medical humanities and that underpin the argument; it then explores the role of language in highlighting the gap in the patient–doctor relationship, before considering the medical gaze and the translation from healthy to sick body and touching on illness as potential catalyst for change. One key aspect stressed by several scholars is the distinction between disease and illness, which stems from the gaze, and particularly the ‘medical gaze’ which was first theorized by Michel Foucault in his 1963 *Naissance de la clinique*, highlighting the separation

4 In a short article published in 1999, Anne Hunsaker Hawkins attests to the ‘ever greater number of people [...] writing pathographies’ from the 1990s and to their ‘remarkable popularity’, particularly among patients looking for information about specific illnesses or treatments. Anne Hunsaker Hawkins, ‘Pathography: Patient Narratives of Illness’, *The Western Journal of Medicine*, 171.2 (1999), 127–29 (p. 127).

5 See for instance Francesca Maltese, ‘Anne François, *Nu-tête*: La femme-roseau’, *Le Carnet et les Instants*, 71, (1992) <<https://le-carnet-et-les-instants.net/archives/anne-francois-nu-tete/>> [accessed 20 February 2023]; Pierre Maury, ‘La douleur et son spectacle: *Nu-tête*, les débuts d’Anne François’, *Le Soir*, 4 September 1991 <[https://www.lesoir.be/art/la-douleur-et-son-spectacle-nu-tete-les-debuts-d-anne-f\\_t-19910904-Z04D2D.html](https://www.lesoir.be/art/la-douleur-et-son-spectacle-nu-tete-les-debuts-d-anne-f_t-19910904-Z04D2D.html)> [accessed 20 February 2023].

made in the medical context between the patient's body and their identity.<sup>6</sup> This distinction led to that drawn between 'disease' and 'illness', and will be key for part of my analysis.<sup>7</sup> Disease is the phenomenon seen from outside, from the doctor's perspective, whereas illness is the interior, subjective, lived experience of the patient. In *Phenomenology of Illness*, Havi Carel points to this fundamental distinction, noting that the doctor can 'only perceive the disease through second- or third-person observation', given that the patient is the only one with the 'full subjective experience of illness': even if patients can 'observe the objective indicators of disease (blood tests or X-ray)', they might not be able to make sense of them – because it's like reading a foreign language.<sup>8</sup> Carel emphasizes how 'illness', as opposed to 'disease', is a complete and existential transformation of a person's life through disruption and breakdown of meaning; this means that there is an enduring distance between patient and doctor.<sup>9</sup> This respective subjectivity and objectivity means they are essentially communicating in different tongues. Similarly, Rita Charon, in *Narrative Medicine* (2006), criticizes how doctors, despite their knowledge of disease and treatment, fail to consider how the patient experiences an illness, or to properly accompany them on their journey through the treatment, beyond its technical aspects.<sup>10</sup>

These distinct perspectives resulting in different use of language are partly the focus of Anne Hunsaker Hawkins's seminal work *Reconstructing Illness* (1999) in which she highlights the fundamental differences between pathographies and medical reporting, based notably on language, style, and tone. Medical reports written by physicians focus on disease and reduce the body of the patient to its 'biophysical components' to record diagnosis and treatment, whereas pathographies' true 'subject is the illness and treatment as experienced and understood by the ill person' and their aim is to 'draw out meaning' from this experience.<sup>11</sup> As such, Hunsaker Hawkins's work was key in emphasizing the significance of narrative in rebuilding a life disrupted by illness and in locating this experience within a larger medical

6 Michel Foucault, *Naissance de la clinique* (Paris: PUF, 2015 [1963]).

7 This distinction between 'disease' and 'illness' and what each term entails in terms of meaning is only possible in English. Our chosen language here enables us to develop a point that could not be made in French where both terms are translated by 'maladie'.

8 Havi Carel, *Phenomenology of Illness* (New York: Oxford University Press, 2016), p. 50.

9 Carel, pp. 15–17.

10 Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (New York: Oxford University Press, 2006), p. 3. Arthur Kleinman makes a similar argument in *The Illness Narratives: Suffering, Healing and the Human Condition* (New York: Basic Books, 1988), see notably chapter 16.

11 Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* (West Lafayette: Purdue University Press, 1999), pp. 12–13.

discourse framework. Arthur W. Frank also contributed significantly to this field with his 1995 *The Wounded Storyteller*. In this, he foregrounded the common narrative patterns used by those who wrote about their illnesses – i.e. restitution, chaos, and quest narratives – arguing that such accounts provide phenomenologically attuned means of translating bodily experiences.<sup>12</sup> In addition, the value of the subjective experience found in illness narratives has been central to the key contributions of Einat Avrahami's *The Invading Body* (2007) and Ann Jurecic's *Illness as Narrative* (2012), both examining autopathographies and their significance.<sup>13</sup>

Like Charon, Hawkins points to the power dynamic and imbalance that exists between patient and doctor and stresses the importance of getting this to change towards a more patient-centred medicine. When *Nu-tête* was written, and certainly when Anne François was receiving treatment in 1981, she is likely to have experienced this disconnect, and used it to inform the novel. While these questions are certainly not unique to a given national context, and much of the theory on the subject can be applied across the spectrum of illness as experienced from various perspectives, most of the research in the field still emanates from the anglophone world and it is essential to reflect on the way writers from a specific country put these various issues to the fore. The 2016 special issue of *L'Esprit créateur* dedicated to French autopathography certainly contributed to bridge this gap in research with a series of articles focusing on French-speaking writers and artists.<sup>14</sup> In this vein, my article seeks to contribute to the visibility of Belgian literature – still deemed liminal – by considering a novel which itself focuses on a lesser discussed form of cancer and the way it frames disease and its language.

### The language of disease versus the language of illness

In *Nu-tête*, Anne François depicts the experience of Cécile W., a 22-year-old whose passion is ballet and who is a few weeks away from a major audition when diagnosed with Hodgkin's lymphoma. The narrative follows a linear

12 Arthur W. Frank, *The Wounded Storyteller: Body, Illness and Ethics*, 2nd edn (Chicago: University of Chicago Press, 2013 [1995]).

13 Einat Avrahami, *The Invading Body: Reading Illness Autobiographies* (Charlottesville and London: University of Virginia Press, 2007); Ann Jurecic, *Illness as Narrative* (Pittsburgh: University of Pittsburgh Press, 2012).

14 Steven Wilson (ed.), *French Autopathography*, special issue of *L'Esprit créateur*, 56.2 (2016) <<https://www.espritcreateur.org/issue/french-autopathography>> [accessed 20 February 2023].

structure and details the various stages of Cécile's illness along with the numerous tests and different treatments she undergoes – almost like a journal. Although the text focuses on Cécile's story, its originality resides in part in the fact that it is written from both her perspective and that of her oncologist, Dr Vanardois. The text continuously switches between Cécile's monologue and that of Vanardois in italics. On a regular basis, the reader can also find letters that act as medical reports from Vanardois to Cécile's GP, informing him of various treatments and procedures, and of her progress.

The polyphonic quality of the text is an interesting feature to reflect upon. Where most pathographies usually focus on only one side of the illness account, François gives a voice, simultaneously, to the doctor and to the patient. The impact of this narrative strategy is multiple and, I argue, enables the author to effectively convey several aspects of the illness experience. At one level, this polyphony highlights the gap in the patient–doctor relationship through their distinct perspectives, mediated by their use of a very different language. This is done by alternating fragments of texts from Cécile's perspective, focusing on her subjective experience of the illness and its treatment on the one hand, and from Vanardois's perspective, focusing on treating his patient both from a medical perspective but also, as will be addressed below, from a far more personal one, on the other hand. Throughout the novel, despite their numerous meetings, there are very few dialogues between Cécile and Vanardois, leaving the reader under the impression that patient and oncologist do not really communicate or work together.

Focusing primarily on her embodied experience, Cécile describes the numerous procedures she undergoes and how she feels, both physically and mentally:

De tous ces examens, je retiens un malaise pire qu'une douleur. Le mal est ponctuel, je peux lui faire face [...]. Mais j'exècre les nausées, les paniques devant les sensations inclassables, l'iode chaud qui court dans les veines et donne envie de crier, [...] les humiliantes secousses de la ponction médullaire, le teint passé au bleu de méthylène, je hais toutes ces pratiques qui vous privent de la souveraineté banale du bien portant.<sup>15</sup>

This example, with its juxtaposition in the same paragraph of corporeal suffering induced by treatments and the psychological struggle that the protagonist finds even worse, draws attention to the way in which the

15 François, p. 38.

hospital and health practitioners treat the body but in essence forget the human being in the process, leaving the patient feeling humiliated. This example also brings to the fore the question of lack of control experienced by the patient through the mention of the loss of 'souveraineté'. François, like many others writing on illness, highlights not only the pain endured but also the extent to which a serious disease and its treatment take over everything else in a patient's life.<sup>16</sup> This question of control remains central to many studies of literature and medicine, and François may have used the writing of *Nu-tête* and Cécile's story as a way to reclaim control over her own experience as a patient. In parallel to these descriptions focusing on the treatment of Hodgkin's lymphoma, the reader also witnesses Cécile's life fall apart, the illness bringing chaos to her life, a point that will be explored in the last part of this article.

As for Vanardois, he comments on Cécile as a patient and on his work as her oncologist in part of his monologues. He describes his work – 'j'observe et je déduis' – and some of the procedures undertaken by his colleagues such as the removal of Cécile's spleen: 'Le bistouri [...] trace une longue ligne rouge. Des pinces écartent les parois de la blessure. Le chirurgien fouille le ventre, repère dans les viscères une masse spongieuse, la rate. Il coupe des canaux, applique des compresses [...] il coud, incise, suture'.<sup>17</sup> He otherwise treats his patient impersonally, reducing her to a body subjected to biomedical treatment, but the distance in their interactions is mainly commented upon by Cécile. It is also worthy of note that Vanardois – contrary to the rest of the medical staff encountered in the novel – uses the *tu* form to address Cécile. This is quite rare in the context of the usually formal patient–doctor relationship and, instead of conveying an attempt on Vanardois's part to narrow the distance between him and Cécile, actually reinforces the power imbalance between the two and the fact that he is the one in control. While commenting on the issue of distance between doctor and patient, the polyphony of *Nu-tête* also enables François to inform readers about medical procedures patients usually want to find out about. At the time of its publication, it was still difficult to find any of these details easily, and the inclusion of accessible information such as these in illness narratives filled a didactic gap.

16 Ogien in *Mes mille et une nuits* and Anne Bert in *Un tout dernier été* (Paris: Livre de poche, 2018), for example, both discuss handling and expressing pain and loss of control over oneself. For an exploration of their works, see Francis Jaouen, 'Dire la douleur dans le cas de la maladie', *Motifs*, 4 (2021) <<https://motifs.pergola-publications.fr/index.php?id=494>> [accessed 20 February 2023].

17 François, pp. 32, 41.

Alongside these two perspectives, what can be considered as the third voice of the narrative is that of the dated letters or medical reports from Vanardois, which regularly appear in the text. These reports, as shown in the example below, offer a very instrumental, scientific, and almost documentary perspective on Hodgkin's disease and its treatment. The language used here is medical and technical, with a distinct tone, style, and specialized lexicon compared to that used by Cécile or Vanardois in their respective monologues.<sup>18</sup> It provides an excellent illustration of the detachment and dehumanization of the body of the patient as an object of analysis while highlighting the medical gaze and effectively exemplifying what Carel defined as 'the appropriation of illness by disease', when the former is no longer a private matter but becomes the latter as an item in a patient's file.<sup>19</sup>

*Sainte-Alice, le 29 mai*

*Honoré confrère,*

*Concernant Cécile W., la coupe histologique du ganglion cervical [...] confirme le diagnostic de la maladie de Hodgkin, forme scléronodulaire. Dans le cadre d'une stadification, divers examens ont été réalisés:*  
 — *tomographie frontale du médiastin: montre une masse lobulée du compartiment antérieur du médiastin moyen;*  
 — *urographie intraveineuse: examen normal;*  
 — *lymphographie pédieuse bilatérale: montre la présence d'une série étagée de ganglions anormaux, de L2 à L5. [...];*  
 — *tomographies computées de l'abdomen: absence d'adénopathie dans les régions pelvienne et rétropéritonéale;*  
 — *scintigraphie hépatique au colloïde sulfuré marqué au TC-99m: foie très discrètement augmenté de volume, d'aspect homogène; [...]*  
 — *scintigraphie osseuse: aucun foyer d'hyperactivité pathologique.*

*Recevez, cher confrère, etc.*<sup>20</sup>

This polyphony results in a text that is both medical and literary. In addition, this dual perspective on the same object, the lymphoma, but from two stances – and three distinct levels of discourse to describe it – provides several pictures to consider and almost oppose the medical practitioners'

18 The formal tone and use of phrases such as '*Honoré confrère*' is at odds with the *tu* used with Cécile discussed earlier.

19 Carel, p. 69.

20 François, pp. 37–38.



instrumental discourse to the lived reality and experience of the patient. In short, this narrative strategy foregrounds at once medical procedures, the medical gaze, and objective medical records in contrast with the patient's subjective experience of symptoms and treatments; it enables Anne François to illustrate the gap between the doctor and patient which was identified and criticized in the works of Charon, Hawkins, Frank, and others from the 1990s, which advocate a change in the way the medical system treats patients. The narrative, whilst never openly criticizing the way the main character is treated by medical practitioners, points out the imbalance of power that exists in the relationship between the consultant and his patient and can be viewed as challenging it. François's own experience of cancer treatment in the 1980s was likely affected by this 'triumph of scientific technological medicine' that is visible throughout the book.<sup>21</sup>

Power is further illustrated by the other side of Vanardois's personality which has a double interest in his cancer patient throughout the novel. The appropriation of illness by disease mentioned above can be metaphorically applied to Vanardois – the seemingly all objective and powerful doctor – and his desire to conquer Cécile – the subjective patient and her illness. Indeed, besides his status as consultant and the medical, more technical aspect of Vanardois's relationship with Cécile revolving around treatments and procedures as detailed above, the reader discovers another layer of the character in his monologues: his fascination for Cécile, with whom he falls in love from their first appointment. A widower, having lost his wife to Leukaemia several years before,<sup>22</sup> he vows to transform Cécile's athletic body into a medicalized one while curing her from Hodgkin's lymphoma, seeing himself as the architect or choreographer of her transformation – 'laisse-moi te déconstruire'; 'je la priverai de son identité' – and ensuring she will need him to rebuild a new self.<sup>23</sup> From the onset, he claims 'elle m'appartient, corps et âme'.<sup>24</sup> Although the focus on Vanardois's personal interest in Cécile certainly appears as a more fictional layer of the novel, I contend that in designing the character of the consultant as one displaying power in his intents, behaviour, and language, François may have wished to represent transgression and abuse of the power he was given as a doctor, in that he can be seen as doing the opposite of what Charon describes in relation to the body and the self. She explains:

21 Hawkins, *Reconstructing Illness*, p. xii.

22 He secretly euthanized her when it became clear she would not survive, highlighting further his power over patients or loved ones thanks to his status as a medical doctor.

23 François, pp. 17, 25.

24 François, p. 11.

Accepting the power and the privilege of touching another's body, interfering with it, hurting it, perhaps healing it incurs in health care professionals profound duties to acknowledge the inviolability of a patient's body as a locus of a person's self. While doctors and nurses might breach the body's unity, we do our best to maintain the 'wholeness' of the patient.<sup>25</sup>

Vanardois therefore has both a professional and subjective interest in Cécile and hides, behind a medical façade, the secret love he develops for his patient; as such, the dichotomy between his seemingly neutral medical discourse and a more power-infused subjective one when it comes to Cécile is not clear-cut in Vanardois's monologues, even more so as the story unfolds.

Through the use of distinctive voices and their respective language, Anne François manages to represent Cécile as a person, as a patient and as an object of desire for Vanardois, along with providing a medical portrait of Cécile through reports and letters.<sup>26</sup> However, beyond the types of language used by each protagonist, it is also worth dwelling on the topic of the body and its language. Cécile's life before and during treatment revolves around her body and control of it, and it is important to reflect on the link between body, language, identity, and illness as the novel also illustrates how medical treatment translates a healthy body into a sick one, and in the process alters the narrator's identity.

### **Medical gaze, body language, and the translation from healthy to sick**

Alongside the alienating nature of the institutional language with which she is confronted, Cécile exemplifies the transformation from person to patient through the gradual dispossession of one's body undergoing hospital treatments. The hospital, described as a maze where everything and everyone looks the same – 'tout se ressemblait, les murs, les étages, les escaliers, les ascenseurs, les gens' – and as 'une administration besogneuse et aseptisée', is also the place of the medical gaze in action and where the voice of the patient is muted.<sup>27</sup> Cécile thus laments how she feels like 'un pan de chair morte

25 Charon, p. 86.

26 Considering Cécile as an object of desire allows to reflect further on Vanardois's ambiguous stance in the novel. Indeed, while secretly in love with Cécile and hoping she will eventually share his feelings, his desire for her can equally be seen as his wish to save her and, in a way, undo his past when he could not save his wife from leukaemia. Looking at the character of Vanardois through this lens provides another perspective and reveals how diseases can equally affect medical staff.

27 François, pp. 7, 81.

offert à des regards indifférents'.<sup>28</sup> This is where, through the fragmentation induced by the various procedures and tests, the healthy disappear and the sick appear. As Carel puts it, 'the appearance of the ill body [...] is made possible because of the disappearance or absence of the healthy body'.<sup>29</sup> Just like the medical discourse mentioned above, the language spoken inside the hospital is one of practicalities, devoid of emotion or empathy. It is formed of commands – 'ne bougez plus, ne respirez plus', 'déshabiliez-vous' –<sup>30</sup> names of machines, procedures and tests (*biopsie, lymphographie, scan osseux, ponction médullaire, chimiothérapie, radiothérapie*, to name but a few), through which, according to Drew Leder, a patient and their disease are 'translated into images, graphs, numbers',<sup>31</sup> in turn providing another kind of portrait of the sick person through medical imagery.<sup>32</sup> The text thus puts forward the typical medical language of measuring, imaging, noticing, confirming, and refining a diagnostic which enables the medical reporting discussed earlier. The picture that is produced of Cécile while in hospital, such as 'le tracé translucide de son système lymphatique',<sup>33</sup> is one made of a different language and data to be interpreted, one that the patient can access – 'one sees one's body as never before. The invisible interior becomes visible, available for one's own scrutiny'<sup>34</sup> – but will not necessarily understand, like a foreign language. This, along with François's use of the fragment, further reinforces the sense of alienation a patient can feel when faced with a new version of their body whose image, disrupted by illness, is now mediated through the language of medical images and that of symptoms, both being difficult to decipher and in which a patient will not easily recognize their own self.

Another articulation between body, disease, and language which underlies the narrative is how illness can be interpreted as a voicing of the body, a language to signal the disease that is as much about the mind as it is about the body as a whole. A lot of the novel is mediated through Cécile's body, which, one can argue, communicates in its own language – i.e. the disease and associated symptoms – something for her to understand. In Charon's words, through illness, '[i]t is sometimes as if the body speaks a foreign language, relying on bilingual others to translate, interpret, or

28 François, p. 71.

29 Carel, pp. 59–60.

30 François, pp. 28, 94.

31 Drew Leder, *The Distressed Body: Rethinking Illness, Imprisonment and Healing* (Chicago: University of Chicago Press, 2016), p. 95.

32 Boyer makes similar comments to François's. See *The Undying*, p. 15.

33 François, pp. 23–23.

34 Carel, p. 74.

in some ways make transparent what it means to say'.<sup>35</sup> In the process of making sense of this language, Cécile slowly comes to realize that, as much as pursuing a cure for her lymphoma, she also needs to reassess her life's priorities, and that her 'previous' life was not doing her any good – 'j'entrevois mon passé comme une erreur géante'.<sup>36</sup> As the story unfolds, it becomes apparent that Cécile has actually been struggling for a long time, and Hodgkin's lymphoma, in which T cells attack healthy cells instead of harmful ones, can thus be interpreted on a more metaphorical level as Cécile's denial of who she really is. While the sick body forces her to stop in her tracks and observe her life, Cécile progressively comes to this conclusion and endeavours to find 'la source du poison'.<sup>37</sup> As such, *Nu-tête*, in the vein of other illness narratives, provides an interesting illustration of the 'crucial role of bodily transformation in self-examination and self-reconstruction practices'.<sup>38</sup>

Cécile's identity, as we have seen, is tightly entwined to her body. A dancer, her body is both a tool and a medium of expression. Her chosen lifestyle and self-discipline leave the reader in no doubt that she intends to push its limits: 'Je n'ai jamais été malade. Je ne fume pas, je bois peu. Je me targue de ma discipline, qui ne m'est pas une contrainte mais plutôt une nécessité'.<sup>39</sup> Throughout the book, Cécile undergoes the process of losing her identity as a healthy person and a dancer in control of her body while becoming a sick person. Both body and identity are slowly deconstructed by the lymphoma and its treatment – 'Mon corps perd sa carapace de muscles, je deviens une forme sans contours, livrée au sentiment de son inconsistance'.<sup>40</sup> As Mathieson and Stam point out, '[b]odily disruption is a serious signal of discrepancy between the healthy and the ill person',<sup>41</sup> and, indeed, the fragmentation of Cécile's body is mirrored by the language she uses to refer to herself. It switches progressively from one of control and discipline, defined by 'actions of *self-regimentation*',<sup>42</sup> to one of resignation as she has to give up her independence and return to her parents' house. More importantly, though, she also has to renounce her dream of joining a

35 Charon, p. 87.

36 François, p. 166.

37 François, p. 101.

38 Avrahami, p. 11. This view is not shared by all scholars in the field though; for example, Ogien believes that trying to find deep meaning in illness is bound to fail. See Ogien, p. 61.

39 François, p. 17.

40 François, p. 51.

41 Cynthia M. Mathieson and Henderikus J. Stam, 'Renegotiating Identity: Cancer Narratives', *Sociology of Health and Illness*, 17 (1995), 283–306 (p. 294).

42 See Frank's work on the various types of ill bodies in *The Wounded Storyteller*, Chapter 2, notably pp. 41–43.

prestigious ballet company and pursuing a career as a professional dancer: 'Après des années d'effort, j'arrête mon entraînement. Je ne ferai pas partie des vainqueurs. [...] J'abandonne'.<sup>43</sup> She trades her capacity to endure physical pain from training to enduring it from treatment – '[a]pprivoiser la douleur me satisfait. Cela ressemble à ce que je connais: l'effort, la volonté, l'orgueil, la maîtrise' –<sup>44</sup> and relinquishes control to the oncologist: 'Je m'en remets au docteur Vanardois. Peu importe qui il est, ce qu'il me veut, et comment il y arrivera. Je ferme les yeux, je me laisse faire'.<sup>45</sup> These examples illustrate important aspects around the perception of pain and illness. Pain is constitutive of many illnesses and can be perceived in a positive or negative light.<sup>46</sup> Cécile is used to pain in the context of her work as a dancer and is willing to treat the one derived from her illness the same way, almost positively. As a protagonist, Cécile exemplifies the tension between empowerment in her willingness to control the pain, and powerlessness as the sickness and effects of the treatments for her lymphoma gradually invade her body, make her quit dancing, and feel like a loser.<sup>47</sup>

As the novel progresses, Cécile's language and behaviour switch from active to passive, compliant, and resigned as she submits to all the tests and medical procedures without questioning them or their effects on her. To use Sontag's metaphor, it is as if she is relinquishing ownership of her body and identity by entering into the kingdom of the sick.<sup>48</sup> This compliance – almost loss of agency – dovetails with Hunsaker Hawkins's observation that 'the model of patienthood in biomedicine is one of passivity'.<sup>49</sup> As patients negotiate their journey with illness, the combination of accepting both the decisions made for them by the medical teams and their new biomedical, foreign-looking and -sounding portrait as a sick person can be characterized as a double withdrawal on the patient's part.<sup>50</sup>

The aesthetics of the body are also at play here. The in-control body of the dancer displaying a heightened version of femininity meets the pathological language and aesthetics of the medical body to become a visibly sick and medicalized body, to the extent that Cécile states that her friends

43 François, p. 17.

44 François, p. 31.

45 François, p. 17.

46 Ogien explores the topic of pain and illness at length in *Mes mille et une nuits*. See notably chapters 1 and 19.

47 For further discussion on this tension, see Avrahami, p. 8.

48 Susan Sontag, *Illness as Metaphor* (London: Penguin Books, 1983 [1978]), p. 3.

49 Hawkins, *Reconstructing Illness*, p. 126.

50 The patient's compliance is commonly explored in illness narratives. See for instance Anne Boyer, *The Undying*, pp. 85–87, where she states that patients also simply comply out of fear.

no longer recognize her.<sup>51</sup> Her body gradually bears and displays the marks of sickness, making the disease inside her visible outside, in what could be labelled the aesthetic language of disease. Cécile's body changes shape – loss of muscle mass, loss of weight – and colour at times during treatment, notably through the use of methylene blue: '[m]on teint vire au gris, mes cernes au parme. [...] mon corps m'est révélé dans des couleurs de boucherie, bleu cobalt et sang cru'.<sup>52</sup> This, coupled with biopsies, blood tests, and surgery to remove her spleen, leaves Cécile with a feeling of complete fragmentation and disembodiment: 'J'aurais voulu que personne ne me voie, que personne ne sache que je me désintègre, que j'erre en pièces détachées'.<sup>53</sup> Here the *style fragmentaire* of the novel – evident in the text's polyphony, its quickly alternating voices, and its layout – highlights, visibly and almost audibly, the fragmentation of the patient's body.

The other obvious change in physical appearance which translates the disease for many into a visible sign of cancer, and is particularly difficult to negotiate for female patients, is hair loss. This is a key element in Cécile's journey and her visible status as a sick person. The stigma associated with hair loss from chemotherapy, and as 'marking' individuals as cancer patients, is well known. It is one of the most striking physical changes experienced by patients. It is portrayed as even more difficult for the protagonist, as the process starts while she is in a public place:

Tout à l'heure dans les toilettes des consultations, je me suis recoiffée. A chaque geste, des touffes de cheveux restaient prises dans les dents du peigne. [...] j'ai pensé devenir chauve en quelques minutes. Je n'osais plus sortir. [...] Je redoutais le moment où il faudrait affronter la rangée de malades alignés dans le couloir. Je suis quand même sortie, les yeux rouges.<sup>54</sup>

Cécile is aware of the gaze of others and that this visible sign of her disease will impact the way she is perceived by society. She decides to shave her head, to wear a scarf, and does not want to be seen without it, admitting she wants to hide 'la vérité de [son] corps' and that 'le regard d'autrui [est] plus dangereux que la lame du rasoir'.<sup>55</sup> It is as if, as Frank observes, she feels that, as the stigmatized person, she must take on the work of 'avoid[ing]

51 François, p. 48.

52 François, pp. 21–22.

53 François, p. 55. In this instance too, Anne Boyer uses a very similar image, referring to her body as 'a car with parts that kept falling off'. See Boyer, p. 87.

54 François, p. 57.

55 François, p. 83.

embarrassing others'.<sup>56</sup> Cécile's comments and behaviour reflect François's desire to use literature as a means to give more visibility to cancer patients in a society which, at least at the time, did not want them to be noticeable. Conversely, although set apart from everyday existence by the visibility of her cancer, Cécile now belongs to another group, that of female cancer patients with whom she shares common signs of illness: 'Je me reconnais dans les femmes drapées et tatouées, je confronte mes marques aux leurs'.<sup>57</sup> Here, it is interesting that Cécile refers to other female patients only; this emphasizes that it is the account of a woman's experience of medicine and how gender potentially affects it. While discomfited by society's gaze on her visibly sick body, this is also a turning point in the protagonist's negotiation of her illness. Instead of further shelving her agency, she makes the decision to shave her head, acknowledging her right to claim her sick body as her own. As such, François's narrative foregrounds the interaction between gendered and somatic identities,<sup>58</sup> and constitutes an effective phenomenological illustration of female patients' corporeal suffering.

From then on, Cécile starts working towards the 'acceptation de se défaire et de se refaire avec un matériau neuf'.<sup>59</sup> Illness, and in the case of the protagonist Hodgkin's lymphoma, therefore appears at once as a devastating experience and as a catalyst for transformation through the opportunity to examine and reflect on her life. This phenomenon has been commented upon by scholars such as Frank. According to his theory of dangerous opportunity, when forced to stop by critical illness and taken to the 'threshold of life', a person has the option 'to choose the life [they] will lead, as opposed to living out the one [they] have simply accumulated over the years'.<sup>60</sup> To an extent, it can be argued that in exploring illness as such an opportunity through the character of Cécile, *Nu-tête* may be considered as François's textual response to the dangerous opportunity that her own lymphoma represented.

In short, François's novel around the experience of Hodgkin's lymphoma and its treatment conveys well how 'life-threatening conditions [are] radically destabilising and leave [...] sufferers in a liminal state of fear, anxiety, uncertainty and chaos'.<sup>61</sup> This is well summarized when Cécile

56 Frank, *The Wounded Storyteller*, p. 31. Kleinman makes a similar point in *The Illness Narrative*, p. 160.

57 François, p. 100.

58 Avrahami, p. 18.

59 François, p. 63.

60 Arthur W. Frank, *At the Will of the Body: Reflections on Illness* (New York: Mariner Books, 2002 [1991]), p. 1.

61 Graham J. Matthews, 'Illness Narratives and the Consolations of Autofictions', in *Autofiction in English*, ed. by Hywel Dix (Cham: Palgrave Macmillan, 2018), pp. 125–43.

says: ‘Je m’efforce d’appriivoiser ce corps qui a été le mien. De démêler la peur de ne pas être aimée, la peur de ne pas exister, et la peur de mourir’.<sup>62</sup> As she slowly recovers, Cécile has to re-evaluate her life and renegotiate her identity, inevitably entailing revisions of her future plans, in line with the transformative capacity of the illness experience enunciated by Avrahami or Hawkins. While getting better and feeling that ‘[s]on corps [lui] était rendu’,<sup>63</sup> the protagonist trades her ballet shoes – part of her old, disrupted story – for trainers, and starts working in a bookshop. Still, she wonders, ‘[l]a femme que je serai, je ne la connais pas. [...] qui serai-je, pour qui?’<sup>64</sup> and while this indicates she has not yet found her new identity, putting to the fore this dichotomy between the “old self” before cancer and the one after cancer<sup>65</sup> enables the author to highlight at once the disruptiveness but also the significance of the experiential side of illness and its potentially positive transformative capacity.

## Conclusion

At the time of publication, *Nu-tête* was one of the very first illness narratives in French to focus on Hodgkin’s lymphoma and, while it is not our claim that the story told in the novel is necessarily the one that Anne François lived, her own experience and knowledge of the pathology certainly contributed to putting this lymphoma into words. While we can interpret François’s desire to put the barrier of fiction between her own experience and the story of Cécile, either as a refusal to be associated with sickness or as a rejection of autofiction as a genre, François’s personal knowledge as a patient undeniably makes for an effective translation of the lived experience of Hodgkin’s lymphoma into Cécile’s story. *Nu-tête* also provides the reader with a relatable account of what it is like to be a cancer patient confronted with a whole new language related to a sick body. As I have demonstrated, what unfolds in the narrative is not simply an account of disease, treatment, and recovery, but a much more complex representation of illness and its impact. Through an analysis of its story and form, which use fragments along with supposedly objective and subjective voices around disease, illness, and patient, I have shown how the novel astutely brings to the fore the visibility and audibility of the experiences of illness in all its phases

62 François, p. 91.

63 François, p. 119.

64 François, p. 17.

65 Mathieson and Stam, p. 299.



of corporeal and psychological disruption, alienation, fragmentation, and translation, at a time when literature, and pathographies in particular, were still a main source of information for patients, serving almost as 'guide-books to the medical experience itself'.<sup>66</sup> François's narrative thus provides a significant insight into Hodgkin's lymphoma and its treatment, while also convincingly engaging with some of the issues that were still at play in medical care in the 1980s, before the supposed shift towards a more patient-centred care – a debate that remains at the heart of many discussions in the field of medical humanities.

As with many illness accounts, one can wonder what pushed François to write a book focusing on a particular pathology. Given the author suffered from Hodgkin's lymphoma herself, one possible and tentative answer may be a desire to reinstate a voice muted during illness by the way the patient was treated in the healthcare system at the time, but also as a means of empowerment to make sense of and restore coherence in her own life story, following the dangerous opportunity presented to her by life-threatening illness. Beyond this, the unusual yet clever mix of discourses used throughout the novel, which makes it so original, enables François to bring into dialogue both the literary and medical fields in which she has a very keen interest, while her use of fragments as a narrative strategy lends itself particularly well to conveying the dismantling effects of Hodgkin's lymphoma on the protagonist's life and body.

66 Hawkins, 'Pathography: Patient Narratives of Illness', p. 127.