

# Who speaks up for Inés Fonseca? Representing violence against vulnerable subjects and the ethics of care in fictional narrative about Alzheimer's disease: *Ahora tocad música de baile* (2004) by Andrés Barba

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## ABSTRACT

This paper studies the 2004 Spanish fictional novel by Andrés Barba, *Ahora tocad música de baile*, one of the first cultural texts dealing entirely with Alzheimer's disease to appear in Spain. It argues that the significance of Barba's fictional novel rests on two important issues: the ethics of representation of violence against vulnerable subjects and the ethics of care. The paper analyses how these two issues allow Barba to create a story in which the verbal and physical abuse to which the person living with Alzheimer's disease is subjected places the reader, on the one hand, as voyeur/witness of the abuse; and, on the other, as interpreter, and ultimately judge, of the fine line that separates euthanasia, assisted suicide and murder. The open ending of the novel defers all ethical and moral judgement to the reader. It examines how the novel offers a monolithic perspective about Alzheimer's disease, in which care is presented as a burden. In fact, this study shows that the novel's multi-layered structure and polyphonic nature places the emphasis on stigmas, stereotypes and negative metaphors around Alzheimer's disease, as found in contemporary social discourses.

**KEY WORDS** – fiction, Alzheimer's disease, representation of violence, vulnerable subjects, ethics of care, stigma, stereotypes, euthanasia, murder, readership.

## Introduction

The rising number of people living with Alzheimer's disease (AD) is slowly starting to be mirrored in the increasing number of life and fictional stories that either give voice to illness narratives that oppose biomedical accounts of

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AD, or stress the burden this cognitive degenerative disease imposes upon family members and/or care-givers. In Spain, the first cultural manifestations devoted entirely to AD appear as late as 2002, the year in which the poetry book *Los cuerpos oscuros* [*The Dark Bodies*] by Juana Castro was published. *Ahora tocad música de baile* [*Could You Play Dancing Music Next?*] by Andrés Barba followed in 2004. The year 2007 saw many releases with Roca's graphic novel *Arrugas* [*Wrinkles*], Mercero's film *¿Y tú quién eres?* [*and Who Are You?*] and the documentary film by Albert Solé, *Bucarest: la memòria perduda* [*Bucharest: Memory Lost*]. In 2008, the film *Amanecer de un sueño* [*Awakening from a Dream*] by Mas Franqueza and Carla Subirana's *Nedar* were screened for the first time, followed two years later by the award-winning documentary film *Bicicleta, cullera, poma* [*Bicycle, Spoon, Apple*] by Carles Bosch and *La mitad de Óscar* [*Oscar's Other Half*] by Manuel Martín Cuenca. In 2011, the documentary film *Las voces de la memoria* [*Memory's Voices*] directed by Dani Fabrà, Vicent Peris and Alex Badia was released. In 2012, the animated film *Arrugas* [*Wrinkles*] based on Roca's graphic novel reached the cinemas, and Pedro Simón published his *Memorias del Alzheimer* [*Memoirs of Alzheimer's Disease*], a book in which he recounts his conversations with Spanish public figures living with AD and/or their care-givers.<sup>1</sup> Within this cultural context *Ahora tocad música de baile* by Andrés Barba, the text that will be the focus of this paper, can be considered a pioneering fictional text about AD in Spain. It narrates the story of Inés Fonseca, a 68-year-old woman who faces progressive neurodegeneration at the beginning of the story and who will be formally diagnosed with AD at the mid-point of the narration. Even though Inés' AD progression is the heart of the narration, the novel is constructed around three main characters to which it gives voice. The importance of Barba's novel rests not only on its novelty within the Spanish context but also on the manner it represents AD: firstly, by not giving voice to the person living with dementia but by basing her portrayal on multiple stereotypes; secondly, because physical violence and verbal abuse flow freely across the narration; and, thirdly, because it confronts the reader with an ethical dilemma, whether Inés Fonseca has been murdered or helped to die with (in)dignity?<sup>2</sup>

According to Judith Butler's discussion with regards to Wittig's ideas on materialism and nature, old age is an idea socially constructed by language for social control (1990: 125); or in Gullette's (2004) terms, we are aged by culture. As a result, at present people living with dementia face a twofold, socially constructed stigma: that of ageing and that of dementia. On the one hand, ageist stereotypes have become a common presence in a social environment in which ageing is perceived as a problem and portrayed negatively (Blaikie 1999; Gullette 2011; Palmore 1999). From this perspective, being old is equated to being ill, disabled, with failed memory, grouchy,

sexless, boring and unproductive (Thornton 2002: 303). Stereotypes such as these spread through cultural texts, media and policies, which preserve and disseminate them in society, and marginalise those belonging to the stereotyped group (Featherstone and Wernick 1995; Friedan 1993).<sup>3</sup> On the other hand, the growing visibility in the media of AD serves the purpose of informing, educating, generating and consolidating awareness about the disease in the public community. On the other hand, it regrettably also has the power of shaping negative social responses to the condition (Gilleard and Higgs 2000, 2005; Leibing and Cohen 2006).<sup>4</sup>

G. Thomas Couser (2004) claims that the representation of vulnerable subjects in life writing, such as the case of Iris Murdoch by Bayley (1998, 1999), brings up numerous ethical questions that range from privacy to exposure. Furthermore, these representations do not normally provide a voice to allow the vulnerable person to respond to the way they are portrayed. Is this also the case in fictional writing? Is fictional writing exempt from ethical responsibilities due to the fact that fiction is generally associated with created or unreal spaces and people? Cultural texts, including literary ones, (re)present society and have the power to shape public opinion: that is, literature can either reinforce hegemonic discourses or can challenge them. The question of the ultimate intention of an author when representing violence against vulnerable people appears to be relevant. Is the ultimate intention of representing violence against a vulnerable subject to provoke empathy towards the vulnerable subject? What if the vulnerable subject is never given the chance to express their suffering? Even more, what if the vulnerable subject is objectified and animalised? Is fiction a safe haven to represent violence against an old woman living with AD and for ageism? As readers, we do not respond homogeneously to the representation of violence. For instance, Susan Sontag has argued in *Regarding the Pain of Others* (2003) with regards to photography and war that (re)presenting atrocity and violence suffered by others may generate diverse and opposing responses: repulsion, shock, pity, sadness, or fascination and attraction.

AD has been at the centre of several life and fictional narratives that either give voice to illness stories that oppose biomedical accounts of AD, stress the burden this cognitive degenerative disease imposes upon family members and/or care-givers, or support and sustain biomedical discourses. In some instances, as pointed out by Zimmermann (2010), AD narratives depict difficult ethical issues, such as assisted suicide or euthanasia. According to Zimmermann, fictional literature links scientific and ethical discourses, 'being able to think through every possible option without having to bear the consequences in that all consideration remains fictional despite the most realistic and imaginable setting chosen' (2010: 102).

One of the novels that Zimmermann uses as the focus of her study is the novel that is also central to this paper: Andrés Barba's *Ahora tocad música de baile*, published in Spain in 2004. Barba's book has not only AD as the main topic, but more importantly it places the reader, as (fictional) witness, in the ethical dilemma of discerning the thin line between euthanasia, assisted suicide and murder. Zimmermann (2010) rightly stresses Barba's audacity in using the fictional text to present the reader through a fictional text with the strikingly psychological and ethical issues – assisted suicide and euthanasia – that surround reality and daily life for AD patients, their family members and care-givers. However, Zimmermann does not make as a focal point of her investigation other important questions that are precisely based on the realistic settings she refers to: the verbal and physical violence to which Inés Fonseca, the person living with AD, is subjected by both male characters, her husband and her son. By making the reader witness these forms of abuse in all their cruelty and crudity, the reader, rather than being an active interpreter, is initially positioned as a voyeur, thus delaying their interpretation of the text until the narration is over. The role of the reader is to witness Inés' planned death; followed by having to make a legal and ethical judgement about Santiago's actions without having been given the perspective of the vulnerable subject and once the narration is over. Nonetheless, following Sontag's (2003) analysis, both Barba's intention and the interpretation the reader makes of that violence depicted can be heterogeneous and contradictory. Consequently, the present paper stresses the importance of analysing the ethical issues inside a novel that Barba has skilfully constructed, based on the extreme psychological and identity effects that AD and ageing have on care-givers and relatives, and their ultimate actions against the vulnerable subject living with AD. Similarly, in Barba's novel AD presents the reader with important familial and societal questions around the duty of care and intergenerational relationships such as reciprocity that are entirely opposed to those sustained by the ethics of care. Unfortunately, it does not give voice to the life narratives of people living with dementia, thus defining them as abject bodies (Kristeva 1982), and stigmatising those living with AD. The novel is in fact not about Inés and her AD, since it does not exhibit her own voice, nor does it intend to serve as testimonial of Inés' experience, but instead it is about the instability of identity of those who can no longer relate to people like her who are living with dementia, the self-in-relation (Maierhofer 2011). Moreover, contrary to the narratives studied by Amelia DeFalco, in *Ahora tocad música de baile* those characters related and caring for the person living with AD are not introduced 'to a new model of relating that provides the potential for ethical witnessing and interpretation, for empathy and the appreciation of another's need' (2010: 82).

Barba's narrative instead of inscribing, preserving, giving testimonial or interpreting the self of the other, presents the lack of empathy of her carers.

Within this context, this paper examines the crucial moments before and after the scene in which Santiago pinches his mother on the hip when they are next to a road packed with cars, making Inés jump, causing her to be run over by a car. What is essential for this analysis is not so much Santiago's conscious and planned act of assisting his mother to die/murdering her, but to deconstruct the textual web of stereotypes about AD that are deployed to serve what seem to be the main purposes of the author: on the one hand, to disclose the complexity of human identity and behaviour, in this case of Inés' husband and two children, through the representation of violence inflicted upon a vulnerable subject; and, on the other hand, to delegate any ethical judgement to the reader once their role as voyeur of violence is over. Fictional texts create what Kaplan has coined as an 'in between' space; a space between reality and fantasy in which 'fictional protagonists, since they do not exist in the lived world, do not have to be responsible to any lived community for what they reveal' (2012: 22). However, as Kaplan states, it is a space that 'can take us to places inside people where we cannot normally go' (2012: 23). Whilst Kaplan's analysis pays attention to places that 'provoke our conceptions and values with images that challenge stereotype' (2012: 23), this 'in between' space, we argue here, imposes an ethical dimension to fictional narratives since they also open the door to reinforcing stereotypes, as well as to facilitating the normalisation of violence against vulnerable subjects.

The terrible effects brought up in the novel are based on scientific and biomedical discourses that emphasise loss and deficits, and that as a result deny personhood to people living with dementia (Kitwood 1990, 1993, 1997; Kontos 2006; Leibing 2006). For instance, Barba's novel creates a voiceless character, Inés Fonseca, whose main feature is defined both in the past and in the present by other characters (her son Santiago, her daughter Bárbara and her husband Pablo) as the embodiment of accumulated deficits, losses and symptoms. Not even in the first stages of her dementia is Inés given the possibility to speak up against a series of accusations and insults she endures from the two male persons in her life, her husband and her son. Inés is soon presented as an empty shell incapable of understanding or feeling, a character with infantile behaviour and physical incontinence, and who no longer is capable of relating to her children and husband in a meaningful social relationship. By the time the scene of Inés being run over by incoming traffic is presented, the depersonalisation and animalisation of Inés has fully occurred through a sequence of realistic accounts of physical and verbal violence. The lack of empathy shown by her children and husband, as well as the centrality that both violence and abuse

acquire in the story, are not the result of the stress to which care-givers are subjected when having to witness deterioration and obliteration (DeFalco 2010: 62). In fact, the lack of empathy seems to respond to a conscious determination by both her son and husband to avenge themselves.

In *Ahora tocad música de baile*,<sup>5</sup> the life of Inés Fonseca is recounted by three main characters: her husband, Pablo, is a retired railway employee who will be the main care-giver and companion; Bárbara, her daughter, is a nurse and a mother of two who returns to work after years devoted to her role as mother and wife; and her son Santiago, a professionally successful young share trader whose personal and love life seems to be quite unstable. These three voices alternate their first-person account with a third-person omniscient narrator that takes over the narration at various times without notice. Inés Fonseca, from the perspective of feminist and disability studies, belongs to several weak classes: old people, the cognitively impaired and women (Silvers 1999). This belonging to three socially marginalised and oppressed groups influences Inés' construction as a character without a voice, but whose past seems to have oppressively influenced the present of the other three characters. Inés represents a sort of spectral subject to which the other three characters violently talk and react: she is a character whose past and personality are (re)constructed by others. Inés' biography is not presented through her memories or through the reconstruction of her memories by testimonials recorded by others (DeFalco 2010: 63), but through the other three characters' personal and subjective construction of Inés as the 'Other'. What is more, these characters write it with the aim of justifying themselves and their present status and actions, which are marked by their hierarchical placement in a society that privileges youth and men over old age and women. Therefore, Inés is characterised through what she is not in relation to her husband, her daughter and her son: she is not young, she is not male and she is not cognitively able.

Emphasis is placed on the identity issues the characters face once Inés' memory starts to fail. In the case of *Ahora*, it is Inés' progressive forgetting, as well as her inability to recognise her family members, that triggers the redefinition, re-articulation and self-invention of Pablo's, Bárbara's and Santiago's identities. However, in contrast to what DeFalco states with regards to other dementia narratives, here the care-giver does not provide 'the testimony the victim cannot longer formulate' (2010: 63). Firstly, Pablo speaks in an imaginary confession narrative to the President of the Spanish Railway Network about Inés' past and present state, and the changes he has experienced such as verbally and physically abusing her, *etc.* These were brought about when he stopped fearing his wife. Secondly, Bárbara explores her own sexuality through a relationship with her young maid, Elena. Finally, the more Inés forgets, the more Santiago

is capable of emotionally distancing himself from her, and the more he can sentimentally relate to other women.<sup>6</sup>

The use of the three voices in the first person, adopting a possible legal confessional tone, according to Senabre (2004), provide the reader with three personal and intimate points of view about Inés' neurological deterioration and a possible justification of Santiago's actions. The legal confessional tone, on the other hand, transforms the reader into a juror who is asked to reach a verdict. *Ahora tocad música de baile* can be also considered novel in line with Mikhail Bakhtin's (1981) concept of the polyphonic novel. This concept of the polyphonic novel refers both to the number of voices and perspectives a narration offers, and to the collective quality of an individual utterance: that is, any linguistic utterance embodies someone else's articulations even when only one person is speaking. In other words, our individual utterance is formed by a multiplicity of voices. According to Bakhtin (1981), Dostoevsky's work exemplifies this polyphonic quality of the novel because it contains many different voices and multiple perspectives that are not subordinated to the voice of the author. In the case of *Ahora*, the plurality of voices and perspectives do not follow a structured or logical sequence, clearly reflecting the chaos surrounding the lives of those linked to Inés Fonseca. Additionally, the multiple perspectives have the effect of creating the illusion of the disappearance of the voice of the author, enabling him to distance himself from the actions and thoughts of the characters created by him. The pretended disappearance of the author also leads to placing the reader as both a participant 'not only in the viewing but in the making of the novelistic universe' (Tanner 1994: 19). In a way, it is this plurality, Inés' silence and the hiding of the voice of the author that allows the latter to present important ethical issues, protected by the 'in between' (Kaplan 2012) space of fiction and by the complex fictional layers designed. The multi-layered voices diffuse and decentre the problematic way in which Inés dies and the violence inflicted upon her, thus assigning their interpretation to the reader.

Inés' silence highlights Barba's acceptance of social discourses that have defined people living with dementia as hollow shells, bodies without minds, living dead or zombies. Behuniak's (2011) study of the social construction of people with AD as zombies shows that this metaphor has been used explicitly or implicitly from within different disciplines, not only the medical one, thus permeating social discourse and catapulting to centre stage the stigma now associated with AD. Given Barba's recognition of coming to AD through Bayley's books and his own research about the disease (Garzón 2004; Montero 2004), it is not surprising that he ends up drawing a picture of AD in which the subject is obliterated.<sup>7</sup> Following the imagery used by socially constructed discourses, Inés Fonseca calls for constant



care from the beginning of the novel, and as for Iris Murdoch, it is through the dissonance between her life before and her life with AD (Basting 2009: 42).

Inés' lack of voice in the novel clearly strips her of personhood, as does her zombie-like status. Personhood is defined as a status or standing bestowed upon one human being, by others, in the context of social relationship and social being. Personhood implies recognition, respect and trust (Kitwood 1997: 8), and Sabat (2002) contends that facets of the self continue even in advanced phases of AD. Ryan, Bannister and Anas (2009: 148) emphasise that the individuals who lack social interaction are incapable of expressing a social identity, losing their social and familial roles, their status within the family structure. Drawing on the definition by Julian C. Hughes of a person as a human agent, a being of this embodied kind, who acts and interacts in a cultural and historical context in which he or she is embedded (quoted in Alvargonzález 2012: 378), Alvargonzález (2012) makes the interesting distinction between the human individual and the human person. Using Kitwood's concept of personhood, Alvargonzález (2012: 380) argues that the constant disassociation between body and mind – not only with regards to AD but in many other circumstances such as paralysis in which an intact brain can no longer control the body – has created a socially constructed depersonalisation. He also claims that the diagnosis of AD, and the disclosing of this to others, transforms the person into a 'demented patient' with a subsequent loss of independence (2012: 381). However, he disagrees with the belief that memory and reasoning are the sole criterion to evaluate personhood, and proposes that both have to be considered alongside the ability to form and hold relationships with others, which implies a central role for feeling and emotion (2012: 381). The socially constructed disassociation between body and mind, human individual and human person (Alvargonzález 2012) seems to be the driving force in Barba's novel.<sup>8</sup>

From the beginning of the novel, Pablo frequently voices Inés' old long-expressed wish to die with dignity. This repetition of Inés' right to a dignified death and the duty of her son to comply with her wishes would displace the possible social guilt from Santiago's final act. Furthermore, all narrators make sure that Inés' emptiness is constantly reinforced and placed in the foreground by the recurrence of some of the most stigmatising symptoms of AD, such as infantilisation, animalisation and resemblance to a zombie. The same can be said about the iteration of grotesque images of ageing and the ageing body that occur on the first pages, which are not only deployed in relation to Inés, but most importantly with regards to Pablo. The contrast between youth and ageing is made explicit many times throughout the novel, thereby creating an obvious equation



between ageing and disability (Chivers 2011: 22). This characterisation of ageing as a grotesque decay and disability is strengthened by Bárbara when she acknowledges the horror felt at the idea of her own ageing, and by Santiago by stating the impossibility of recognising his mother and by ridiculing his father. In addition, Pablo projects his own frustration with his ageing – retirement, financial constraints, boredom, inactivity, *etc.* – on to Inés neurodegenerative problems, and exercises psychological abuse and verbal violence against her. Pablo is characterised as a maniacal old man who lives in the past, always remembering what he was before retiring, even fictionally addressing his boss in a form of confessional style. Even though Pablo and Inés are only in their late sixties, they seem to have been depicted older than they actually are, due to the accumulation of stereotypes of decay that are attached to both of them, but specially to Pablo, *i.e.* Pablo's greed and obsession with money, his lack of activity and intellectual interests, his constant living in the past, *etc.*

The third-person narrator who opens the story states in line three, with regards to Inés, that: 'un gesto que parecía traído de muy lejos, de la infancia quizás' ['a gesture that seemed to be brought from the distant past, perhaps from childhood']<sup>9</sup> (Barba 2004: 13). In fact, the story starts when Inés is 68 years old – Pablo must be around the same age – with the third-person narrator emphasising her infantilisation by referring in the opening paragraph three times to childhood – 'infancia' [childhood], 'niña' [young girl] and 'juguete' [toy] (2004: 13). Strikingly for the reader, the first line of the second paragraph transcribes Pablo's words to Inés after she has almost emptied the salt shaker on the soup: "Eres una vieja imbécil" (a veces la llamaba así, para disgustarla), ya no vas a poder tomarte la sopa' ["You are a stupid old woman" (he sometimes addressed her that way to upset her), now you will not be able to have the soup'] (2004: 14). The infantilisation and the abusive language that Pablo uses establish the tone of the story, with the objective of creating an oppressive and decaying atmosphere that will slowly lead to the naturalisation of violence against Inés.

Childish behaviour and body decay are presented as Inés's identity features. Cultural narratives have equated ageing with a return to an infantile behaviour and dependency, while the fragility and decay of the body are traces of the inevitability of death. The image of the ageing body as a walking memory (Featherstone and Wernik 1995: 19) emerges in the novel but as an empty walking body, as a zombie. It does so through the spatiality of the house as a metaphor of Pablo and Inés' declining or lost memories and the permanence of the (aged) body/house:

La casa era esto; una estructura de memorias que les constituía a los dos y que se agotaba a su sencillo mostrarse, como si en realidad no hubiera nada que

comprender tras ella aparte del hecho de que estuviera allí. Si la hubieran quemado o derruido, probablemente habrían muerto ellos también, Inés y él, como muere un miembro al separarse del cuerpo que lo constituye, sin aspavientos, en un acto perfectamente natural. Y, de la misma forma, si ellos murieran, la casa no podría tampoco sostenerse, o lo haría tan dislocadamente, tan desde lejos, que produciría quizás la misma sensación de desvalimiento que un moribundo abandonado a su suerte.

[The house was just this; a structure of memories that constituted them both and which ran out at its simple display, as if actually there was nothing to understand behind the structure apart from the fact that it was there. If it had been burned down or demolished, they probably would have died too, Inés and he, like the death of a limb when separated from the body that forms part of it, without fuss, in a perfectly natural act. And, in the same way, if they died, the house could not stand either, or it would do so too dislocated, from too far away, that it would produce the same feeling of helplessness as a dying person abandoned to their fate.] (Barba 2004: 15)

As a structure containing memories, the house is described in its bodily character, thus constructing an indelible link between body as the house of memories and as the embodiment of memory (Katz 2013). The importance of the image of a mindless body from the first pages stresses the formation of a concept of personhood based on a cerebral 'brainhood' figure, which made it possible to isolate the person who became a victim of faulty memory (Katz 2013: 310). Thus in *Ahora*, references to the body as an already empty house surface throughout the book with great intensity:

Una casa vacía es como tu cuerpo de ahora, salta un recuerdo y retumba su eco en el vacío hueco de tus ojos mirándome.

[A house is like your current body, a memory emerges and its echo resounds against the hollow gap of your eyes looking at me.] (Barba 2004: 131)

La realidad insultante del cuerpo de su madre, envejecida e inconsciente pero no lo bastante como para que no se la pudiese reconocer en algún rasgo ... así parecía que todo el cuerpo de su madre se había convertido en una fotografía.

[The insulting reality of his mother's body, aged and unconscious but not enough not to be recognised in some feature ... it seemed that the whole body of his mother had been transformed into a photograph.] (Barba 2004: 147–8)

The lines transcribed emphasise the conception of the mind as the only one capable of expressing and containing memory, hence ignoring the possibility of its expression through the rest of the body (Kitwood 1993, 1997; Kontos 2006; Sabat 2002), and rejecting the emotional character of memory. Therefore, personhood is denied to the person living with dementia, a notion that strengthens as the plot evolves. Barba skilfully builds the story on the basis of a series of well-known symptoms that medical discourses around AD have persistently emphasised and which have influenced its

cultural representations: loss of words and memory; repetitive behaviour; difficulty choosing appropriate clothes; disinhibited and infantile behaviours; problems controlling bladder and bowel; failing to recognise others – who are you?; getting lost and wandering around; needing the formal care of the nursing home; and lacking understanding of time and place. Each of these symptoms corresponds to the three stages of AD: early stage, middle stage and late stage, which parallel the first three movements of the four around which the novel is structured.

For instance, the beginning of the second movement narrates the important moment of the diagnosis from the point of view of Pablo, who feels helpless. As readers, we are taken through the diagnostic moment from Pablo's emotional perspective, which creates a nightmarish picture and characterises the doctor as unsympathetic, with a strong temperament (Barba 2004: 84–7). All the questions asked of Inés are the common medical ones: date, time and where the person is; or whether the person can remember a short list of words, follow instructions and do simple calculations. Nevertheless, they are presented here as a series of rapid sequences of incoherent exchanges between the doctor and the patient, adding to the frightening quality of the scene. The ultimate acknowledgement of having been diagnosed does not come with hearing the name of Alzheimer's disease, but instead with Pablo's rejoicing in how humiliating the diagnostic moment had been for Inés, whilst the possibility that she might live up to another 15 years is depicted as a burden. Interestingly, the word Alzheimer's is not given, either before the diagnosis or at the diagnostic moment. It appears for the first time in the part that follows the diagnostic encounter, which is narrated from the point of view of Bárbara (Barba 2004: 90). She is the first to name the disease with which her mother has been diagnosed; but instead of focusing on Inés, Bárbara goes on to emphasise the terrible emotional consequences AD has on care-givers:

Por mucho que nos empeñemos no es tan fácil cuidar de alguien que ni si quiera te reconoce, porque cuidamos para que nos cuiden, o para que nos lo agradezcan, o para justificarnos, pero cuidar a quien no tiene rostro es cansado como morir una y otra vez, y mi madre se sienta siempre ahí, en ese sofá.

[No matter how hard we try, it is not so easy to care for someone who does not even recognise you, because we care to be looked after, or to be thanked for it, or to justify ourselves, but caring for those who have no face is as tiring as dying over and over again, and my mother always sits there, on that sofa.] (Barba 2004: 91)

The significance acquired by the diagnostic moment, the different stages and symptoms of AD, as well as the complete silence of the person living with dementia, together serve to assign all weighting to the deterioration, obliteration and loss of human dignity. Even Pablo, the only one who

could truly be called a care-giver, relates key moments in the progression of Inés' AD by underlining the significantly dehumanising symptoms (e.g. losing control of bladder and bowel).

Animalisation and infantilisation as recurrent dehumanising techniques and metaphors, as well the body/house metaphor, reach a climactic and shocking moment for the reader by the end of the story. As new symptoms surface, the hollowness of Inés' aged body intensifies, mirroring her big large hieratic picture hanging in the wall of Santiago's living room. In addition, as Inés' unresponsiveness progresses, the abusive and violent attitude of the two male characters towards Inés increases. Her husband's verbal abuse intensifies, from firstly calling her 'old lady' to then calling her 'old bitch'; later he sexually abuses her by undressing her at the nursing home with the purpose of 'watching' her naked. Santiago, on the other hand, goes from the morbid fascination he feels for his mother to the moment in the story when he physically abuses her by beating her up: a moment that precedes the one when he makes her jump into the incoming traffic. In the third movement, the omniscient narrator recounts Santiago's resentment against his mother, as he wishes for her death. The hieratic aged and abject body of Inés is also compared to the immobile and immutable body appearing in the photograph: that is, it is totally void of meaning (Barba 2004: 149–50). Once Inés is put in a medicalised nursing home, which in the novel is also called 'clínica' [hospital], contrary to what Santiago had expected, Inés' oppressive presence in his life increases in such a way that it becomes unbearable for Santiago, thus leading to his final decision causing her death. However, first Santiago beats her up:

La segunda [vez] el golpe que le propinó fue un poco más fuerte. Y fue como si con aquel *juego* se abriese todo un mecanismo al que *se estaba rindiendo sin querer, fascinado* en la posibilidad que le ofrecía ahora estar solo con ella, tenerla allí junto a él en el sofá de su propia casa, tocarla, pensar que podía hacer daño ... no decía nada, no se revolvía ... respondió con un sonido gutural y sordo.

Era solo un animal. Un animal con un estómago que debía ser rellenado para seguir viviendo, que necesitaba beber al día al menos un litro de agua, que defecaba y orinaba, que olía ... Al cuarto golpe reaccionó Inés con un grito.

[The second time, the blow given was a bit harder. And it was as if with that *game* he was *unwillingly giving himself up* to a new situation, *fascinated* by the possibility of being alone there with her, of having her there next to him, in his own house, of touching her, of thinking that *he could harm her* ... she did say nothing, she did not react ... she responded with a guttural and muted sound.

She was just an animal. An animal with a stomach to be filled to continue alive, who needed to drink at least one litre of water a day, who defecated and urinated, who was smelly ... After the fourth blow, Inés reacted with a scream.] (Barba 2004: 256–7, my emphasis)

Although after the fourth blow Inés reacts mildly, the recurring comparison to an animal, as well as her identification as an abject body with merely physical needs, make her living conditions appear grotesque and humiliating; thus they serve the purpose of displaying her death as possibly liberating. For instance, the sadistic physical abuses to which Inés is subjected by her son seem to have been placed in the novel as a conscious narrative motif in order to link the abuse to what will happen next: Santiago ‘facilitates’ the death of Inés in response to her mindless and dehumanised state. However, the relief felt by all three characters after Inés dies seems to justify Santiago’s actions, along with a surprisingly aesthetical description of Inés’ dead body. Therefore, Barba’s fictional book appears to create a space for ageism as well as for abusive behaviour against vulnerable subjects such as old people and people living with dementia. In the fictional ‘in between’ space, Barba makes visible and possible what is socially not only unethical and amoral but also illegal (Zimmerman 2010). It can be argued, following Butler’s analysis in *Precarious Life*, that the novel opens up ‘the space for a legitimate public debate, free of intimidation’ (2006: XVII). The reader can either emotionally attach to Inés’ terrible decay and depersonalisation, and hence identify with her; or the reader can identify with the burden of care and the identity crisis other characters are experiencing. However, Barba’s silencing of the vulnerable subject and her abjection could easily be naturalising the use of violence against vulnerable subjects like those living with AD. Moreover, Agamben’s (1998) concept of *homo sacer* could also be employed to explain the status of Inés Fonseca: she is both different from animal life, which can always be sacrificed, and from human life, which can neither be killed nor sacrificed without punishment. She is both included and excluded from law, thus the interpretation of her death is threefold: she has been killed, assisted to die with dignity or sacrificed. Only the reader will have the power of deciding in which of the three ways Inés’ death should be interpreted; but for that interpretation the reader’s understanding of the concept of care plays a fundamental ethical role.

The concept of care, when understood as an ethical issue, confers to care some sort of responsibility that emerges from people’s relationships with others (Gastmans and De Lepeleire 2010; Tronto 1993; Van Hooff 1995). The ethical duty to care for another human being is part of our existence as subjects/individuals (Gastmans and De Lepeleire 2010: 84). In addition, the way in which we think about being old structures our moral reaction to the Fourth Age, thus sustaining the life’s stages as the model to follow (Silvers 1999). However, the voices of the informal care-givers (Pablo and occasionally Bárbara) and relatives (Santiago) are the ones heard in Barba’s book. They are the ones narrating the cognitive

impairment Inés faces through their own self-narrations. Furthermore, with the exception of Pablo, who is the only one portrayed in specific situations of informal care – dressing, feeding, bathing, *etc.* – Inés’ two children do little in terms of daily caring for her. For instance, Bárbara does the grocery shopping for her parents, while Santiago is completely disengaged from any family matters and duties. From the narrative accounts of these three characters, those who interplay with the people living with dementia, what arises is not the autonomy and dependency – interdependency – (Tronto 1993) of both care-giver and the receiver of care. Not even Hettema’s (2014: 497) call for the centrality of the receiver of care as a person with capacities is presented. On the contrary, the personal narrative of the people living with dementia as a way of expressing their identity (Gubrium 1987) is totally absent in *Ahora tocad música de baile*. As articulated by Bárbara in the previous quote, Inés’ care-givers do not feel that reciprocity is part of the care of Inés any longer and as a result they solely focus on stressing her deficits. Additionally, as Silvers (1999) stresses, intergenerational solidarity is required in order to achieve a fair ageing; but this solidarity cannot be achieved unless new structures of intergenerational mutual understanding of the differences among generations are put in place. *Ahora tocad música de baile* clearly departs from this mutual understanding to enhance the separation and the lack of communication and solidarity between generations. In fact, Barba’s novel presents only two alternatives for the people living with AD, and in both cases their autonomy and personhood are denied: on the one hand, the pathologising medical facilities of the nursing home in which to await death; on the other, death.

Highlighting deficits and symptoms, languishing in the physical and verbal violence inflicted on Inés, leads us again to the discussion about the ethical responsibilities of fictional writing. There are two aspects that require a detailed analysis. On the one hand, the sadistic depiction of violence in *Ahora* seems to blur the limits between fictional representation and fascination or even pleasure. On the other hand, making a vulnerable subject the object of such violence, even within fiction, may have, as it has already been pointed out, the unwanted effect of naturalising it. Moreover, the way in which Inés dies and the resolution of inner conflicts that follows are clearly linked to Dostoevsky’s psychological novels such as *Crime and Punishment* or *The Brothers Karamazov*. In fact, whereas in Dostoevsky’s narrative the focus is the possible ethical justification of murder, in Barba’s novel the ethical issue is the thin line between assisted suicide and murder. It is the reader’s role, using his or her own judgement and ethical approach to the event, to determine whether Santiago murders his mother or commits an ultimate demonstration of love by both assisting her to die with ‘dignity’ or scarifying her to liberate those around her.

Precisely because judgement is ultimately passed on to the reader, it is necessary to raise the question of whether the aesthetic representation of violence as fiction affects the reader's response to this text. That is, whether it is the fictional quality of the text that predisposes the reader to justify the violence portrayed in terms of its aesthetical quality; or, on the contrary, the representation of violence increases the empathy of the reader towards the person upon whom violence is inflicted. The reader of this novel becomes a sort of a witness and voyeur (Sielke 2002; Tanner 1994) who does not have the ability of stop the violence (Misri 2014: 31) and therefore just gazes at an already-objectified person, further stripping Inés of any potentially remaining humanity and perpetuating the violence that reduces an old woman to an object (Tanner 1994: 18).<sup>10</sup>

The ethics of fictional representation has been at the centre of the debate in creative writing (Cosgrove 2009; Gandolfo 2011), in literary theory and philosophy (Gibson 2002; Levinas 1989; MacIntyre 1981; Nussbaum 1986, 1990; Parker 1994; Schwartz 1997), and in feminist and ageing studies (Butler 1990; Gullette 2004; Silvers 1999; Tanner 1994). For instance, Nussbaum (1986, 1990) argues that there are some truths about human life that can only be expressed through fictional writing, because literature expresses better than philosophy the conflicts between value systems. In addition, fictional works on ethics and empathy (Harrison 2008; Keen 2007) have stressed how the reader's empathy towards certain subjects increases in fiction and therefore readers tend to identify themselves with fictional characters and their ethics more often and more strongly than with real others. Furthermore, Keen (2007) argues that narrative empathy is a strategy used by contemporary novelists who consider human emotions to be universal. *Ahora tocad música de baile* needs to be studied from this perspective: fictional narrative both presents to the reader a highly stigmatised depiction of AD and people living with dementia, and deploys a crucial ethical issue surrounding dementia; the thin line between assisted suicide and murder, as well as the ethics of care in which abuse and violence cannot play a part. The relief the characters feel somehow counteracts the tension created in the narration by the moment of the tragic assisted accident when Inés dies and is grotesquely depicted once again:

Y el afán de vivir era tan intenso en ellos que tenían la sensación de que se lo estaban robando a la agonizante. Allí estaba tendida Inés. Inmóvil. La cercanía de la muerte la había despojado. Tenía una pierna virada en un ángulo imposible. La falda se le había levantado hasta la cintura. El antebrazo derecho le cubría el rostro.

[And the desire to live was so intense in them that they had the feeling they were stealing it from the dying Inés. Inés was there, lying. Motionless. The immediacy



of death had bared her. She had one leg in an impossible angle. The skirt had been pulled up to the waist. The right forearm covered her face.] (Barba 2004: 263)

This horrifying description of Inés can certainly underline that the intention of the author may have been to make the reader empathise with her as a person. However, by offering at this point in the narration a clear contrast between the desire to live of her husband and her children and the broken and lifeless body of Inés, the scene seems to be serving the purpose of leaving the story open to interpretation. As a result, Barba's fictional novel becomes a space in which the different faces of the ethics of care and the ethics of representation of violence are depicted and problematised. The possible empathy that the reader could feel towards Pablo, Santiago and Barbara is immediately counterbalanced by the dehumanised broken body of Inés.

In his review of the novel, Ricardo Senabre (2004) stressed its open ending. This open ending, he argues, has been enabled by the confessional tone created by the use of three voices in first person. As mentioned before, these voices provide the reader with three personal and subjective perceptions of Inés' neurological deterioration and the possible justification (or not) of Santiago's actions. In fact, if Barba's intention were to recreate a legal deposition/confession, his conscious use of this narrative style would open up a narrative space for the reader in which to make a legal and ethical judgement. The three points of view, as well as that of the omniscient narrator, form an interwoven view of the situation: they never offer an ethical resolution. Hence, this open ending delegates the authority of the resolution to the reader's ethics of care, leaving the story without a definitive closure until the act of interpretation itself (Fish 1980). The verdict, murder or assisted suicide, would depend solely on the reader's position, thus creating a text without an ending that can be interpreted *ad infinitum* (Derrida 1976). Chekhov once insisted that the writer's duty is: 'to describe a situation so truthfully ... that the reader can no longer avoid it' (Gordimer 2010: 423). The final portrayal of Inés clearly serves this purpose: the reader/voyeur, unable to stop the violence while reading, can no longer avoid making a moral judgement about Santiago's actions, and also about the manner in which all other characters – including society represented through its institution – act with regard to a person living with AD once the narration is over. Whether this decision favours sympathising with Santiago's actions, or cathartically rejecting the abuse committed by Pablo and Santiago, is left for the reader to decide. Nonetheless, if attraction and fascination are also part of the possible reader's response, then the vulnerable subject living with AD is transformed into the object through which violence becomes attractive.

## Conclusion

Despite being one of the first Spanish cultural texts devoted to the topic of AD, *Ahora tocad música de baile* by Andrés Barba (2004) can be characterised as a fictional novel that encapsulates a vast, rich and varied set of views, stereotypes and conflicts around AD, people living with dementia and their care-givers. Even though Inés Fonseca is the centre of the story, her voice and perspective are not offered, thus enhancing the perspectives of those three characters with a voice in the book alongside the third-person narrator; all perspectives which *create* and *reinvent* her past to produce a greater contrast with her current state. Their perceptions of Inés living with AD do not differ from those perpetuated by the stigma associated with AD, depicting people living with dementia as zombies, as hollow and decrepit bodies that cannot react to brutal physical and verbal abuses, and are therefore denied personhood. It is precisely the idea of the emotionless and mindless body that is highlighted throughout Barba's book which leads to three important issues: first, the emotional and social consequences of ageing and of living with AD – Pablo and Inés; second, the relational identity problems that the act of not being recognised by the other creates in the subject – as seen in Santiago and Bárbara; and third, whether a mindless body that is conceived by others as a burden should be afforded the right or duty to die. The Alzheimer's hell (Gravagne 2013: 139) into which the reader is submerged runs parallel to the psychological impact Inés's AD has on her children and husband, but does not voice the personal narratives of people living with dementia. This way, the novel by Barba becomes a fictional textual space in which factually pressing ethical issues such as the thin line that separates euthanasia and murder are presented (Zimmerman 2010) but not resolved.<sup>11</sup> *Ahora tocad música de baile* cleverly places the final judgement, or ethical decision, on the shoulders of the readers. The novel's fictional presentation of assisted suicide or murder opens the novel to the discussion of ethical issues, but its representation of violence and the stigmatising depiction of the person living with AD clearly problematises the social responsibility that fiction plays in perpetuating and naturalising violence, discrimination and stigma against vulnerable subjects.

## NOTES

- 1 Most of these Spanish cultural texts dealing with AD have been studied by Medina (2013, 2014) and Prout (2012). It is interesting to note that film seems to be the favourite media to (re)present and discuss AD.
- 2 It is problematic to talk about dying with dignity when the character is pushed into incoming traffic, as shall be analysed.

- 3 Spanish news media have portrayed the rise of an ageing population as a financial burden for the whole nation.
- 4 Rowe and Kahn's (1987) ideas about successful ageing shifted the focus from age-intrinsic to age-extrinsic and from treatment to prevention. However, this notion of successful ageing imposed even more pressure on older people. It is not the goal of this article to give a full account about the development of the concept of successful ageing, its interpretations and critiques which, on the other hand, have been analysed in great detail by Morten Hillgaard Büløw and Thomas Söderqvist (2014).
- 5 *Ahora tocad música de baile*, similar to the structure of a symphony, is divided into four movements: the first movement, Christmas 1999; the second movement, May 2002; the third movement February to April 2003; and the fourth movement, July 2003. As in a symphony, the four parts correspond to exposition, development, recapitulation and coda. Moreover, the first three movements mirror the three stages of AD: the early, middle (in the case of Inés Fonseca the moment of diagnosis) and late stages, the last when Inés Fonseca is placed in a private, medicalised nursing home. The coda, the fourth movement, encloses in Barba's novel an emphasis on the resolution of the problem: Inés' death restores for the other three characters the sense of stability that existed before the first symptoms of AD started.
- 6 It would be interesting to do an analysis of the relationship between Santiago and Inés from the perspective of psychoanalysis and the Oedipus complex. The castrating mother figure of Inés as represented in the novel was a constant, for instance, in the Spanish cinema of the 1970s and 1980s.
- 7 As Pamela Gravagne (2013: 129) has studied, both Bayley's books about Iris Murdoch's life, and the film based on them, present the image of Alzheimer's hell.
- 8 Alvargonzález uses his proposal to discuss the ethical challenges around AD when dealing with issues such as assisted suicide, euthanasia or death with dignity. He considers that the human person remains through relationships, and even through the emotional links established by others to them, even after death, thus he claims that euthanasia for terminally ill Alzheimer's persons cannot be justified on ethical grounds because, when this euthanasia is practised, the two cardinal virtues (firmness and generosity) come into intractable contradiction (Alvargonzález 2012: 384).
- 9 All translations into English from the original in Spanish are by the author.
- 10 This novel could be also analysed from a feminist perspective. In this specific instance, it could be argued that the reader gazes at Inés and the violence she is subjected to through Santiago's and the narrator's male gazes.
- 11 There are two recent films that present the death of a cognitively impaired old woman by suffocation, the French film *Amour* (2012) by Michael Haneke and the Mexican film *Las Buenas Hierbas* (2010) by María Novaro. In *Amour*, the husband suffocates his wife, while in the Mexican film it is the daughter. Although both films end with a similar action, the interpretation of the suffocation with a pillow of the cognitively impaired old woman has been multiple. For instance, M. M. Gullette (2014) expresses her concerns with the possible interpretation of the film as supporting euthanasia since it can be perceived that the lives of older people are worth ending. But she also underlines the possibility of interpreting the film as a way to foreground the stress, the exhaustion and isolation of the care-givers. In the case of Novaro's film, I would argue, the suffocation is framed in a very different manner by constructing a context of reciprocity and intergenerational solidarity between mother and daughter, in

which womanhood is the only way out from patriarchy, and the strong link between nature and the human life is made explicit.

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