

From the medicalisation of dementia to the politics of memory and identity in three Spanish documentary films: *Bicicleta, cullera, poma, Las voces de la memoria* and *Bucarest: la memòria perduda*.

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### **ABSTRACT**

This paper explores how the concept of Alzheimer's disease (AD) is constructed through Spanish media and documentary films and how it is represented. The article analyses three documentary films and the cultural and social contexts in and from which they emerged: Solé's *Bucarest: la memòria perduda* [*Bucharest: Memory Lost*] (2007), Bosch's *Bicicleta, cullera, poma* [*Bicycle, Spoon, Apple*] (2010), and Frabra's *Las voces de la memoria* [*Memory's Voices*] (2011). The three documentary films approach AD from different perspectives, creating well-structured discourses of what AD represents for contemporary Spanish society, from medicalisation of AD to issues of personhood and citizenship. These three films are studied from an interdisciplinary perspective, in an effort to strengthen the links between ageing and dementia studies and cultural studies. Examining documentary film representations of AD from these perspectives enables semiotic analyses beyond the aesthetic perspectives of film studies, and the exploration of the articulation of knowledge and power in discourses about AD in contemporary Spain.

### **KEY WORDS**

Alzheimer's disease; dementia; identity; citizenship; personhood; documentary film; memory; Spanish politics.

You can recycle the heart; you can recycle the kidney, but you cannot recycle memories; you cannot recycle your brain.... Being a human being, an entity, is our mind. His body will be there, but his mind is gone. (*Biclicleta, cullera, poma*)

Alzheimer's disease (AD) is predicted to affect 25%-30% of the over 65's in developed countries by 2050 (Special Committee on Aging United States Senate 2011). AD does not discriminate against gender, race or class, but affects mainly the ageing section of the population. It has become extraordinarily difficult not to know somebody who, in one way or another, is touched by AD. Thus it is present in all areas of our society, from family relations to policy-making. The need to address the health and social problems that AD is creating globally, nationally and locally appears simultaneously in many different disciplines: medicine, pharmaceuticals, biotechnology, social sciences, care practices, health policies, architecture, and culture. Communicating facts about AD is essential for specialised communities, but what really matters on a large scale are the discourse practices that tackle AD as their object of knowledge. After all, these discourse practices shape the way society perceives and represents AD, and therefore might have the final responsibility for either socially centring or marginalising the group of people living with the disease.

It was not until the 1980s that AD attracted the attention of politics, science and industry. From the 1980s onwards, patient and family associations started to emerge, and stories about AD surfaced in the media, in cultural texts and in public discourses. As Moser points out, AD is 'a reality and social problem in need of collective and political intervention locally, nationally, and internationally.... [AD] is a global matter of concern' (2008: 100).

Alzheimer's disease used to be regarded as simple senile dementia. Only in recent years has there been an attempt by the medical community to make the public aware that AD is instead a progressive and irreversible neurological disorder which results in a deterioration of all cognitive functions. In recognition of this fact there has been a shift in treatment for AD patients from psychiatry to neurology, which sets apart AD from other types of dementia. From a health economic point of view, AD will become the greatest health problem for

society since it requires long-term palliative care which, as it stands, would be unsustainable for national health systems. In Spain, population forecasts to 2050 show the number of people living with AD rising to 1.5 million as a result of an increase in the percentage of persons over 65 – 30 per cent of the total population (Anon 2011a). In 2011, approximately 600,000 people in Spain had been diagnosed with AD, and another 200,000 were believed to be suffering from the disease without having had a medical diagnosis (Anon 2011a). This staggering number, when taken in combination with the documented scarcity of nursing home places<sup>1</sup>, diminishes the chances for a person with AD to secure an adequate place to live in and to receive appropriate care. Apart from class and gender implications, what emerges from these figures is that the family replaces public health and social care as the main actor in providing care for older people and of AD patients. Furthermore, the family can be left with the entire financial burden and responsibility for care regarding AD (Peón Sánchez 2004).<sup>2</sup>

The epidemic nature of AD has forced policy makers and national governments to invest the financial resources available in three main areas: first, medical research to find a cure for the disease or at least ways to prevent it; second, pharmacological palliative care; and finally, support for caregivers, such as information, training, psychological assistance, etc.. None of the three areas, however, have the ‘real’ person at the centre of their interest.

The starting point for this paper is the conception of language/image as the embodiment of system of thoughts (Althusser 1969; Foucault 1994) which informs how we think and perceive AD. The paper is structured as follows: an overview of the (re)presentation of AD in social sciences, media and politics is given; focus is then shifted to new documentary films in general, and the three documentaries at the heart of this study in particular. Through an analysis of the documentary films and some epitexts, the main part of this article shows how cultural productions perpetuate and/or question power and social discourses around AD. A comparative analysis of the three films and the means by which they aim to influence or shape public perception and opinion is the main focus of the analysis. As Philo (2008) argues, media ‘have a key role in sustaining and developing some ideologies’ (540), therefore cultural texts can be regarded as either agents of change by counteracting the stereotypes present in contemporary society, or as instruments to maintain current power and social discourses.

Within social sciences, the academic study of dementia has been approached mainly from two perspectives: the sociology of health and illness, and the sociology of knowledge. Both perspectives have dealt with issues and concepts developed by the biomedical, social-psychology and social-gerontology disciplines. What emerges from some approaches to dementia and disability is that illness 'is the antithesis of the norm and ideal of a healthy mind and body and brings with it associations of dysfunction and deviance' (Innes 2009: 3). Others, however, consider that impairment is the rule while 'normalcy is the fantasy' (Davis 2002: 30). Whatever approach is taken, it is clear that drawing the line between normalcy and deviance is highly difficult and problematic.

Klienman's (1988) distinction between illness and disease is of great importance when analysing and contrasting medical and personal discourses around AD. As he explains, whilst disease is 'the practitioner's perspective' (5) and therefore in biomedical terms it is 'reconfigured *only* as an alteration in biological structure or functioning' (5-6), illness 'refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability' (3). As Bond (1992) has suggested, biomedical discourse, by defining the disease as an abnormality of terrific proportions, has highly stigmatised those suffering from AD. Biomedical discourse has dominated the public sphere, shaping a fearful public perception of the disease. It has also influenced the social and political responses to AD by successfully attracting policy makers and research funds to the arena of the medical search for a cure. Bond's study on the medicalisation of dementia points out the favourable and unfavourable aspects of this process, and explains how it has exercised its expertise and social control, as well as leading to the individualisation and depoliticisation of behaviour (1992: 400). From a Foucauldian perspective it can be argued that the medicalisation of dementia, and therefore of AD, is a controlling force, due to the fact that knowledge is a socially-constructed category through which power manifests itself. If AD is socially constructed by discourses used in order to control the experiences of those living with AD and to legitimise powerful narratives assigned to AD, then it is possible, as Hardin and Palfrey have done (1997), to challenge what is 'known' about AD. The picture of AD emerging from these socially-constructed discourses is that of a body without a mind, of a hollow shell: that is, a picture in which AD obliterates the subject, and calls for constant care either by the family members- informal caregivers - or by formal caregivers, at home or in nursing home facilities. The emphasis then is placed on confinement and separation as the only way to deal with persons living with AD. The social burden for the caregiver,

represented by both the disease and the confinement - formal or informal - displaces the sufferer and places the caregiver at the centre.

Kitwood and Sabat challenge focusing on the caregiver and call for placing the individual with AD at the centre of all discourses about the disease. Within this social-psychological approach to AD, Kitwood's concept of personhood emerges (1990, 1993, 1997). Personhood is defined as 'a status or standing bestowed upon one human being, by others, in the context of social relationship and social being. It implies recognition, respect and trust' (Kitwood 1997: 8). Sabat (2002) argues that aspects of the self remain in AD even in advanced phases. By distinguishing three forms of self, Sabat as well as Kitwood, proposes in 'Mind, meaning and personhood' (2006) a person-centred approach to care. Brooker defines this person-centred care as a combination of four factors: valuing people with AD and their carers; treating people with AD as individuals; looking at the world from the perspective of the individual with AD; and creating a positive social environment in which the person with AD can experience a relative well-being (2002: 216-19).

Social gerontological approaches play a crucial part in the study of dementia. Among the different approaches of social gerontology, critical gerontology stresses that old age is a social construction (Thornton 2002). AD then has to face a twofold social construction, that of ageing and that of dementia. Within this development, the 'cultural turn' in gerontology described by Gilleard and Higgs (2000) has finally opened up the field to the study of representations of ageing and AD in cultural texts.

Ageist stereotypes in Western culture, from the classical period to the present, have gained strength in a social environment in which ageing is perceived as a problem and portrayed negatively (Palmore 1999; Atchley 1997). The general connotations of being old - ill, disabled, with failed memory, senile, sad, lonely, grouchy, sexless, boring, lacking vitality, in decline, unable to learn and unproductive - 'unwittingly work to displace older people from their communities into situations of being undervalued, unproductive, less capable, and dependent' (Thornton 2003:303). Furthermore, stereotypes spread through cultural productions, media, and policies, hence perpetuating them in the social structure, and empowering collective ideologies by marginalising those belonging to the stereotyped group (Featherstone and Wernick 1995; Friedan 1993). Even though several studies illustrate the scarce appearance of news in the Spanish media focusing on older people and the ageing process (Bueno 1996; Fernández and Muñoz 1994; González and Szurek 1990), Spanish

news media have portrayed the rise of an ageing population as one important cause of Spain's financial deficit. To the already existing ageist stereotypes playing an important role in everyday social culture in Spain, the over 65 population in Spain has to also endure now being portrayed as a financial burden for the whole nation.

In the 21<sup>st</sup> Century, stereotypes of AD have joined the pre-existing stereotypes of ageing, stigmatising those who live with it and, in Gillespie's terms, producing 'little more than an oversimplified approximation of the [AD] condition' (1997: 5). It was in the mid 1980s when the stigma was created in Spain through the constant use of a vocabulary with negative connotations: cruel, regrettable, sad, implacable, sufferer, victim, demented, violent, burden, bad behaviour, *etc.* (Malingre Pérez *et al.* 2010: 20-23). The increasing visibility of AD in the Spanish media<sup>3</sup> not only serves the purpose of informing, educating, generating and consolidating awareness towards the disease in the public community, but also has the power of shaping social responses to it. Lakoff and Johnson (1999:270) have emphasised that metaphorical expressions are not in language but in thought, therefore they shape the way we think and act. Undoubtedly this is the case of the metaphors, myths or stereotypes about AD spread by Spanish media and thereafter rooted in Spanish society<sup>4</sup>, which have significantly contributed to its negative perception and status in contemporary Spanish society.

Contemporary society is devoted to creating meaning and understanding through cultural artefacts. The impact of cultural artefacts in the contemporary public sphere is enormous and shapes how we perceive, talk about, and act (Jameson 1981). Therefore, our starting point is the concept of culture as the everyday processes and practices of creation of meaning. From this perspective, cultural artefacts dealing with AD shape how we as social subjects perceive, think about and act in relation to this disease. Culture puts facts into context, so cultural artefacts can either sustain hegemonic discourses or question them. Even though film, poetry, fictional and non-fictional narratives of AD had already flourished globally by the end of the 20<sup>th</sup> Century, in Spain it was not until 2002 that the first cultural manifestation devoted entirely to AD materialised, in the form of the poetry book *Los cuerpos oscuros* [*The Dark Bodies*] by Juana Castro. It was followed by Barba's novel, *Ahora tocad música de baile* [*Could You Play Dancing Music Next?*] in 2004; while Roca's graphic novel *Arrugas* [*Wrinkles*] and Mercero's film *¿Y tú quién eres?* [*Who Are You?*] were both released in 2007. It was also in that year that the documentary film by Albert Solé, *Bucarest: la memòria perduda* [*Bucharest: Memory Lost*] was released. In 2008 the film

*Amanecer de un sueño* [Awakening from a Dream] by Mas Franqueza was screened for the first time, followed two years later by the award winning documentary film *Bicicleta, cullera, poma* [Bicycle, Spoon, Apple] by Carles Bosch. In 2011 the documentary film *Las voces de la memoria* [Memory's Voices] directed by Dani Fabrá, Vicent Peris and Alex Badia was released; and finally, in 2012, the animated film *Arrugas* [Wrinkles] based on Roca's graphic novel reached the cinemas.

It is of particular interest to contextualise this cultural production representing AD within the socio-political and discursive frames in which this cultural production emerges. In 2005, the son of Adolfo Suárez, the first democratically-elected Prime Minister in Spain after Franco's dictatorship, announced on television that his father was suffering from AD. Suárez's last public appearance dates back to 2003, and the only image of him as a person living with AD dates to July 2008 when King Juan Carlos I visited him. Since then very little is known about Suárez, but the media coverage at that time was crucial for the dissemination of a stigmatised representation and perception of AD. In 2007, Albert Solé, son of Jordi Solé Tura, one of the founding fathers of the Spanish Constitution of 1978 and Minister of Culture under Felipe González from 1991 to 1993, released *Bucarest: la memòria perduda*, in which he reconstructed the life story of his father and disclosed that Jordi Solé Tura had been suffering from AD since 2000.<sup>5</sup> Also in 2007, Pasqual Maragall, the prominent Catalan politician, former Mayor of Barcelona and ex-President of the Catalan Government, was diagnosed with AD. Maragall, then 66, publicly announced that he had been diagnosed with early onset of AD. In 2008 he created the Pasqual Maragall Foundation for Research into Alzheimer's, whose main objective since its launch has been to promote scientific research into AD. As part of the foundation's initiative, as well as to support raising awareness, *Bicicleta, cullera, poma* (Carles Bosch) was released<sup>6</sup>. Since his public announcement, Maragall's name appears in almost every other piece linked to AD being published in the Spanish media.

The three documentary films previously mentioned - *Bucarest: la memòria perduda*, *Bicicleta, cullera, poma* and *Las voces de la memoria* - not only approach and represent AD from different perspectives, but create well-structured representations of both hegemonic and counter hegemonic discourses of AD in contemporary Spanish society. All three will be analysed next, by exploring how the concept of AD is constructed through the media in film epitexts and documentary films, how it is represented and how epitexts shape audience

reception of the film and perception of AD. The three documentary films embody different responses to the medical and socio-economic discourses around the disease in Spain. They mirror the current state of discourses and practices around AD at a global level that, as Moses suggests, 'do not simply co-exist, but also interfere with one another in complex ways that contribute to make certain enactments present or absent, visible or invisible, dominant or marginal, more real or less real' (2008: 109).

### **A new documentary film**

Since the late 90's, Spain has witnessed the boom of documentary films produced for the big screen. The documentary film genre in Spain had been mainly confined to TV thematic channels and programmes, and therefore only very few Spanish documentary films before the late 90's had made it to the big screen and had received public acclaim. Among the few exceptions, two documentary films produced in 1976, a year after Franco's death, greatly influenced the genre: Basilio Martín Patino's *Canciones para después de una guerra* [*Songs for After a War*] and Jaime Chavarrí's *El desencanto* [*The Disenchantment*]. Spanish viewers had to wait another twenty to thirty years to see the genre thrive further. Javier Rioyo - *Asaltar los cielos* [*Storm de Skies*](1999); *Extranjeros de sí mismos* [*Aliens to Themselves*] (2000) - Carlos Saura - *Flamenco* (1997); *Fados* (2010) - José Luis Guerín - *En construcción* [*Under Construction*] (2001); *En la ciudad de Sylvia* [*In the City of Sylvia*] (2007) - Julio Médem - *La pelota vasca* [*The Basque Ball*] (2003) -and Carles Bosch - *Balseros* [*Rafters*] (2002); *Bicicleta, cullera, poma* [*Bicycle, Spoon, Apple*] (2010) - are all award-winning documentary film directors whose documentaries have been screened in cinemas around the world<sup>7</sup>.

In documentary films, filmmakers record social and cultural issues which they consider to be important for our understanding of the subject they present. Documentary films have as their main purpose to inform and persuade the viewer to hold some attitude or take some action with regard to their subject (Nicholls 2001: 2). In this way, the documentary film is the most effective way to enhance understanding of a given subject on a mass level (Ellis and McLane 2005: 326). Bruzzi highlights the emergence of a *new documentary* form in the 21<sup>st</sup> Century with the increased popularity of documentaries in the cinema, the advent of reality television and the formatted documentary (2007: 1). She also indicates the



performative character of the documentary and claims that the relationship between image and reality in a documentary film is not straightforward. The documentary is representational and the spectator realises that 'a documentary is a negotiation between reality on the one hand and image, interpretation and bias on the other' (Bruzzi 2007: 5-7). The three documentary films under study have a very similar structure and all three show a particular tension between the aim of factual representation - with clear influences of reality TV - and the impossibility of achieving this, given the clear ideological positioning the films adopt<sup>8</sup>. From the presence and participation of the director Albert Solé in his documentary, to the directors' illusionary absence in *Bicicleta y Voces*, all three directors deploy similar techniques that range from interviews, close-ups, point of view shots, to reaction shots.

### **Synopses<sup>9</sup>**

*Bicicleta, cullera, poma:* In this film Maragall allows himself to be portrayed alongside his family and doctor, in order to leave a record of his everyday personal struggle with AD. This film follows Maragall for two years, from his visits to the doctor to the creation of the Maragall Foundation to promote research and help scientists find a cure. Set mainly in Barcelona, this film shows the Catalan politician's great efforts to raise awareness and resist progressive cognitive impairment.

*Voces de la memoria:* A documentary about the therapeutic power of music in AD and how it alleviates the deterioration and preserves the essence of personality beyond memory. It follows for several months the daily routine of a choir composed of thirty people suffering from this disease. The documentary tells the story of the choir and its members, from the first rehearsals in the day centre to the performance in the Palau de la Música in Valencia before hundreds of people. The documentary also allows a deeper understanding of the characters, showing their family life and the radical change that AD operates on the patients and their families.

*Bucarest: la memòria perduda:* This follows the personal pursuit of Albert (a journalist born in exile in 1962) to rediscover his roots, within a double exile. His father, the Spanish politician Jordi Solé Tura, who became a key figure during the Spanish Transition, was forced into exile for his political views against Franco in the late 50s. Now, after a life full of fascinating personal and political experiences, Jordi has launched a new internal exile: his

fight against AD. This documentary tries to recover the memories of historical figures such as Santiago Carrillo, Jorge Semprun, Manuel Fraga and Jordi Pujol, with little known episodes of the struggle against Franco and the Cold War. For Albert, many of these experiences are vague memories of a child. Therefore he travels from one exile to other, trying to restore the memory of his family and his own memory.

### **Film and epitexts**

Stanitzek borrows Genette's (1986) concept of epitext and places it within the context of film (2005: 36-37). Film epitexts are all texts surrounding the film text: film posters, trailers, stills, synopses, promotional press releases, etc. Film epitexts such as synopses are placed outside the film text itself, but greatly influence its reception by predisposing the viewer towards a targeted reception of the film's meaning and purpose. Undoubtedly the contexts in which synopses appear are also of significant importance, because the synopsis appropriates the film text with the goal of enhancing and promoting the context itself. Therefore an analysis of epitexts provides 'an account of the social and political structures which underpin the content of texts' (Philo 2007: 186). The following two synopses of Maragall's documentary film are good illustrations of both the appropriation of the film text with the aim of promoting the context in which the synopsis appears, and the purpose of influencing its reception. On the one hand, the website of the Seattle International Film Festival (SIFF), *Bicicleta, cullera, poma*, presents this documentary film as follows:

As both the former mayor of Barcelona and former president of Catalonia, Pasqual Maragall has been a *popular leader* for the people of Spain. In 2007, this charismatic public figure was diagnosed with Alzheimer's. *Bicycle, Spoon, Apple* is an up close and personal account of his *decision to go public* with this *revelation*, of his steadfast determination *to beat* the disease, and of *the strength and support of his family* (including his optimistic wife Diana Garrigosa) during his *struggle to fight* it.

Following Maragall for two years, director Carles Bosch (who helmed the Oscar-nominated documentary film *Balseros*) creates an *intimate portrait* of the man and his family, expanding his focus to *doctors* and *scientists* for a more *complete picture* of Alzheimer's, its *myths*, and the current state of *research*. The title comes from three words used to test patients' memories, and is used in one of the more

affecting scenes in which we see the *stoic* Maragall crumble ever so slightly when he can't recall them. By bringing us so *deep into the life of an Alzheimer's sufferer*, Bosch *demystifies the disease* - resulting in a documentary that's sure *to leave viewers forever changed*.

'Touching, uplifting and informative'.—*Variety*

'It's a must-see'.—*The Stranger*

'What makes this Spanish documentary different and potentially border-crossing is its *extraordinary hero*, Pasqual Maragall'.—*Hollywood Reporter*

'An enthralling portrait of a man, Pasqual Maragall (...) this is a movie full of light, of *hope*, of *life*'.—*Cinemanía*

(<http://www.siff.net/cinema/detail.aspx?FID=242id=44326>; authors' emphasis)

On the other hand, the Pasqual Maragall Foundation (PMF) presents it this way:

BICYCLE, SPOON, APPLE has been supported by the Pasqual Maragall Foundation and has recently been chosen to participate in the official selection of the San Sebastian International Film Festival (out of competition). Directed by the oscar-nominated director Carles Bosch (*Rafters, Septembers*) and produced by Cromosoma, *the film is an approach to Alzheimer's disease after diagnosis from a scientific, human and emotional perspective*. The documentary features *first-person testimonies* of Pasqual Maragall and his wife Diana, their three children, and their relatives and close friends, together with scientists and other patients, offering *a moving and courageous story*.

BICYCLE, SPOON, APPLE shows a history of *struggle* and *hope*. For two years a team has followed this *unique patient* in his *crusade* against Alzheimer's. With intelligence, candor and humor, Maragall is followed along his *daily routines*, his *appointments with the doctors*, with *his family* and in *the Alzheimer's Foundation he is promoting* to approach a problem that affects 26 million people worldwide and that *can only be beaten by scientific research*.

BICYCLE, SPOON, APPLE has been produced by Cromosoma with the participation of TVC, TVE, XTVL, ICIC and ICAA. The film has its premiere in October and will earmark part of its profits to the fight against Alzheimer's through the Pasqual Maragall Foundation. ([http://www.fpmaragall.org/en\\_actualitat/1357/](http://www.fpmaragall.org/en_actualitat/1357/); author's emphasis)

The first, most prominent feature emerging from both epitexts is their conscious inclusion of the documentary film within the context of the mainstream film industry of Hollywood. They both make explicit reference to the Oscar nomination and previous career of the director Carles Bosch, although the SIFF takes a step further and includes excerpts from the film reviews published in well-established film industry magazines. Clearly the SIFF text aims to legitimise both the festival and the documentary film, with its inclusion within the hegemonic discourse of the Hollywood film industry. Additionally, the SIFF synopsis deploys a discourse in which the local, the national and the global character of the film are highlighted in order to promote the Film Festival to its local, national and international audiences and costumers. On the other hand, the PMF synopsis eludes any spatial limits and reinforces the global aspect of the documentary film and of the disease.

The second aspect in need of analysis is the emphasis placed by the SIFF text on the public figure of Maragall, his leadership and his 'decision to go public with his revelation'. This sentence in itself, as in the case of cancer and AIDS (Sontag 1991: 5), implies quite negative aspects hidden under the act of disclosing being a sufferer of AD and indirectly refers to the general assumption that characterises AD as something to be ashamed of, a sin that one must publicly confess (Foucault 1977). For instance, Maragall is transformed in this epitext into an 'extraordinary hero' of epic dimensions who is determined 'to beat the disease' and whose 'struggle to fight it' becomes exemplary. In contrast, the PMF text omits any mention to the public role Maragall has played in Spanish and Catalan politics. The only mention of Maragall is accompanied by the epithet of "unique patient" which intentionally relocates Maragall's public figure within the depersonalised realm of those living with AD. Therefore this text deliberately puts the main focus on the disease itself and on how it affects the life of the person living with it and his/her family. Although living with the disease is also described in warlike terms such as 'struggle' and 'crusade', here the metaphors expand from personal to social, from Maragall's particular daily experiences with AD to his efforts to

finance and promote scientific research because AD ‘can only be beaten by scientific research’.

The differences and similarities between both texts are evident, but what is then the primary aim of the documentary film? How do they present the purpose of the film? How do they prepare viewers for their interpretation? In the case of the SIFF the synopsis aligns with those of fictional mainstream films based on a star-system. Maragall is simultaneously the main actor and the main character of the documentary film; he is both fictional and real. The film is about his fight and its main purpose is to provide an ‘intimate portrait of the man and his family’ with the aim of ‘bringing us so deep into the life of an Alzheimer’s sufferer’. Hence the text is appealing to the reality television quality of *Bicicleta, cullera, poma* to attract the viewer’s attention, while displacing the scientific and medical to the background. It can be argued that the SIFF epitext prepares the viewer for making a personal and emotional interpretation of the disease by centring the plot in human suffering and heroism. In the PMF epitext, however, Maragall is enacted as a *first-person testimony*, a symbol of all patients of AD, who guides viewers through his twofold crusade against AD: personal and scientific. The main purpose of the film is not only to enter into Maragall’s private life with AD, but to do this through his social and altruistic role in promoting scientific research to find a cure for AD in the future. Maragall’s heroism is not located, in this epitext, in his daily personal battle against AD but in his daily social battle against the disease. This synopsis then predisposes the viewer to take a social stance along with an emotional one.

### **From the medicalisation of dementia to person-centred care and citizenship**

*Bicicleta, cullera, poma* and *Las voces de la memoria* are similarly structured around a film team following for several months the main character/s of the story. Both texts can thus be described as film narratives of ongoing processes in which the camera is transformed into the lens through which viewers can witness what are deemed to be real life events. The chronological nature of the filming process offers the opportunity to establish the documentary film as the means for capturing reality as it is, and to offer the viewer the illusion of perceiving long duration events condensed into a few minutes. However, as Bruzzi (2007) has studied, a documentary is representational and therefore the spectator is impelled to interpret facts ideologically deployed. In the case of these two documentary films, the main

purpose is to convey factual representations of the effects of AD in the persons living with it and their daily interactions.<sup>10</sup> Even though both documentary films are released and produced within one year of each other, they both confer a diametrically different account of AD. While *Bicicleta, cullera, poma*'s focal point is the disease process itself, *Las voces de la memoria* presents the interpersonal environment of the person with AD as its focus.

*Bicicleta* depicts AD as a global phenomenon through the first person account of Pasqual Maragall. Maragall plays the role of someone with AD in which two approaches intersect: that of the patient and that of the biomedical sphere. Set mainly in Barcelona, nevertheless the documentary film presents the disease in another three locations: the United States of America, Holland and India. Although the different settings of the medical practices—hospitals and health centres—reflect the financial situation of the country they are based in and their particular cultural idiosyncrasies, the common element to all three is the diagnosis of AD and the disease itself. Moreover, these three locations, represented by the doctors as researchers, are reunited in the single space of the Pasqual Maragall Foundation Think Tank meeting in Barcelona, where researchers from around the globe gather to discuss strategies and developments from a biomedical perspective: early detection and intervention.

At the core of the narrative is Maragall's intention of changing the role assigned to his person as a victim of the disease, to that of an agent who can bring about change and hope through his altruistic campaign to raise funds for research on AD. It is precisely his public figure, his political influences and his social status that allow him to become an agent of change. In addition, his campaign is organised in such way that the viewer is sometimes presented with a political campaign-like narrative in which office staff, family members, friends and public converge around him and therefore position him as an agent of change or moral figure.

Maragall's personal journey through the symptoms of the disease's early stages, and his fears, describe a passage to an inevitable cognitive deterioration, through which he gives voice to the person, not to the patient, and to the social agent, not to the victim. However, this personal account is framed within a medicalised perspective of AD from the beginning of the documentary film, thus creating an intertwined narrative that places its focus on the discovery of a cure and locates the person with AD outside the boundaries of normalcy. Furthermore, this medicalisation of the disease excludes the subject and his illness narrative from the centre of attention. It is the medical quest for a cure, an early diagnosis, a delay in the onset and the

slowing of the progression of the disease, which turns into the focal point of *Bicicleta*, as stated by the American neurologist Ronald Petersen in the film, in order to prevent the collapse of health care systems in the world. In consequence, Maragall's narrative reinforces the perspective of a depoliticisation of behaviour (Bond 1992: 397-403) by displacing the necessary social provision of care to those living with Alzheimer into the family realm. These are in fact the perspectives of the two prevailing discourses of family members and of the medical researchers, which result in the dissolution of the representative voice of Maragall. By the end of the film, their constant allusions to the uncertain future, Margall's progressive decay, or the lost freedom of his wife, become the main narratives. What is presented at the end of *Bicicleta* is a Maragall confined to the family space and medical facilities. Even with his main cognitive abilities still properly functioning, the film puts into focus Maragall's journey to oblivion, thus perpetuating socially-constructed discourses which dispossess the person with AD of their citizenship even before the disease has progressed to cognitive incapacity. It is in fact the visually powerful scene of the disposal of Maragall's car that serves as a metaphor of Maragall's state, according to those social discourses.

*Las voces de la memoria*, on the other hand, presents the viewer with a radically different perspective of AD. The goal of the therapy presented is to retrieve emotional memories through music and to display its achievements publicly with a concert. *Voces* does not refer to doctors or researchers, but to therapies; it does not focus on one figure but on a whole group, and follows the life of six different persons. These six persons, as well as all members of the group, men and women, do belong to different age ranges -from 59 to 85- to different social classes, and have diverse educational and intellectual backgrounds. What they have in common is AD and music, but each of them experiences the disease at different stages and with diverse symptoms. Through their daily routine of musical therapy, the viewer is offered a new perspective on the disease, one in which the focus is person-centred care and where selfhood is enhanced through music. Here what prevails is the illness narrative (Bury 2001; Hunsaker Hawkins 1999; Kleinman 1988) through which people living with AD overcome social isolation and affirm personhood (Ryan, Bannister and Anas 2009).

Furthermore, *Voces* presents the viewer with the patient's counter-narrative to medical and social discourses (Diedrich 2007). The space of the day centre becomes the microcosm of a world in which normalcy is the fantasy (Davis 2002: 30). Emilia Peinado, 85 years old, is unable to recognise her own family members, but many other cognitive skills are

still intact in such ways that she acknowledges that '*la memoria es lo único que me falla. Todavía servimos para mucho*' ['memory is the only thing failing me. We can still contribute a lot'] thus overriding the social stigma associated to both ageing and AD. Carmen Martínez, 70, repeats over and over the same words and sentences, or presents repetitive and compulsive behaviour, but still shows clear signs of social behaviour by means of dress code and use of makeup (Sabat and Harré 1992). Antonio Lonches, 78, is unable to remember his past and does not recognise anyone, but displays a great sense of humour and continues to live a 'normal life' (Adasiak 1989). Antonio Olivo, 59, a helicopter pilot who had to take early retirement due his early detection of AD, keeps up a normal life and visits his former colleagues. The case of Candi Bonilla, 85, presents the viewer with the ultimate reality of AD by the end of the film. Her deterioration is the most evident from the beginning and is used as an example to show that even in the most advanced stages of the disease communication is still possible, and therefore personhood has not vanished. The only reaction to her surroundings comes when Candi's son plays the compact disc of the choir.

*Las voces de la memoria* raises some fundamental issues surrounding AD and sets out with a clear intention of placing AD in a dialogical perspective with issues such as isolation, social and health care matters, personhood and even citizenship. Isolation from social life is the most common effect on AD's patients and their families (Alzheimer's Society). Protecting patients from the social stigma attached to the disease can also result in their isolation and withdrawal from any social life at a time when maintaining social relationships is still possible. *Voces* explicitly underlines the beneficial effects of preserving AD patients' social interactions. Not only are the interactions within the day centre sustained, but also the daily interaction with family members and other people in the public space. All six protagonists are shown outside the space of the day centre at some point during the documentary film, with the main purpose of illustrating the different degrees of social interaction and communication a patient may have depending on the stage of the disease. This dialogue within public and private spaces in AD is reinforced by the organisation of concerts, such as the one in the Palau de la Música de Valencia on 26 September 2010. For instance, the sequences of the concert emerge as a powerful metaphor for the public depiction of the 'normalities' of the disease. The striking contrast between the darkness in which the audience is enclosed and the luminosity of the stage in which the choir is performing metaphorically vindicates both the ability of the patients to communicate and the social centrality they ought to have.



This dialogical structure of *Voces* also affects the dynamics between the individuals and the group that the documentary film evokes. While the notion of grouping is evident, it is placed only within the sphere of the day centre and the concert. Each patient is shown as a separate, independent individual who is defined by his/her relationships with others in both private and public spaces, hence placing their social interactions as the focal point of the documentary film. Thus the documentary stresses the important role that preserving the individuality of each participant plays not only for the self but for the group as a whole. The latter clearly confers agency on the AD patient, recognising a person with AD “as a social actor, capable of exerting power and influence” (Barlett and O’Connor 2007: 110), who will express his/her political agency in diverse manners (Bauman 1992) such as taking centre stage to show the audience that persons with AD can function through, for example, music. In this sense, Barlett and O’Connor have rightly called for a revision of the terms of personhood as described by Kitwood – ‘a standing status that is bestowed upon one human being by others in the context of particular social and institutional interactions’ (1997: 7) and of citizenship - a status bestowed on members of a community by which they are conferred equal rights and duties - when dealing with dementia. Barlett and O’Connor question the narrow scope of these two concepts when applied to patients with dementia. Furthermore, they argue in favour of a ‘broader sociological theoretical base’ (2007:115) in which ‘persons with dementia are thus seen simultaneously as both actors in constructing their own reality, and constructed by prevailing discourses’ (Barlett and O’Connor 2007: 114). Similarly, *Voces* underlines this simultaneity by presenting a group of individuals whose common feature is AD, but who are also constructed by prevailing discourses such as those of class and gender. Their interactions with other patients, day centre staff, or family members, along with their way of dressing and caring for keeping certain social etiquette, are all dependent on discourses of power. Therefore, all patients in the group act as both persons and citizens. Nonetheless, the degree to which they are affected by the disease is not the same for any one of the individuals, which is an aspect that emphasises the need to recognise the different facets and effects of AD, and the common mistake of positioning all AD patients under an exclusively homogenising label.

There are further important features of *Las voces de la memoria* worth mentioning. On the one hand, there is the effacement of any precise geographical location, even when, on the basis of the language spoken and the concert hall itself we can identify the city as Valencia. What is important, then, is the disease *per se* and not where it is located; the axis is

formed by those who are affected by AD and how better to care for them within the given social structures. Unfortunately, not all patients living with AD have the opportunity of securing a place in this kind of day centre facilities where innovative therapies are implemented. As a study carried out by the Spanish *Consejo Superior de Investigaciones Científicas* illustrates, the availability of spaces in Day Centres and/or Hospitals for AD patients only accounts for 0.64 per cent of these. Furthermore, 68 per cent of the spaces available belong to the private sector (Blanco Pérez-Rubio 2011: 57-58).

By publicly acclaiming the benefits of these therapies, *Voces* places the accent on the social need for spaces in which AD patients are given the opportunity to socially engage with the world that surrounds them. This idea is similarly reinforced by the context in which the documentary film can be viewed. The documentary film is presented on two platforms: one as the 57 minute documentary film in its linear version; and the other as an interactive documentary film in which the web user can have first-hand experience of musical therapy via on-line games, learn more about the disease through the six persons/characters of the documentary film, acquire deeper knowledge of musical therapy through well-known experts in AD, and finally actively share experiences and memories through an internet and radio application. It is from this second interactive platform, in which the linear documentary film is embedded, that the ultimate meaning of the project flourishes as a social and collective enterprise in which patients and non-patients need to get involved. That is, it is a social responsibility to adopt an active role in widening AD patients' social interactions, and this can only be achieved if they are provided with the right care to enable them to preserve their personhood and citizenship.

### **Collective memory, cultural memory, historical memory and history**

It is important to recognise that *Voces* establishes another level of interpretation for the concept of memory, which goes beyond the biomedical discourse. The character of the songs employed for therapy determines a concept of memory that is linked to those of collective memory and individual memory. According to Halbwachs, 'It is in society that people normally acquire their memories. It is also in society that they recall, recognise, and localise their memories' (1992: 38). It is therefore belonging to a group which provides the materials for individual memory, even if the individual has never experienced events directly. Most of the songs sung by the choir are spatially rooted in Spain, and cover a time span from the end of the 19<sup>th</sup> Century to the 1970's. From La Tuna<sup>11</sup> song '*Clavelitos*' [*Little Carnations*] to

the *ranchera* '*Me gustas mucho*' ['*I Like You Very Much*'], popularised in Spain by the Spanish singer Rocío Durcal, all the songs have been present in the Spanish collective memory. Musical therapy, as explained before, aims at communicating through emotions. What this musical communication involves is individual memory through the medium of a collective memory, rooted in cultural memory. It can be argued that Nora's notion of the 'lieux of mémoire' as 'any significant entity, whether material or non-material in nature, which by dint of human will or the work of time has become a symbolic element of the memorial heritage of any community' (Nora 1996: XVII) is presented here in the form of music. Even though Nora does not consider popular songs as sites of memory, it is clear that these songs in *Voces* are ones around which collective and individual memories are constructed. Furthermore, these songs exist to help, in this specific case, to remember the past, whether it is a construction or not. In fact they help recall the past for patients and audience alike, and help locate both groups at the same level of cultural and social interactions.

*Bucarest: la memòria perduda* (2007) by Albert Solé is, in his own words, a metaphor about Alzheimer's and memory loss (Anon. 2009) which surpasses the mere exploration of forgetting in AD. In *Bucarest* viewers are thus confronted with an intricate narrative in which the concepts of memory and forgetting undertake a metaphorical leap in order to enclose political, social and cultural aspects. In so doing, this documentary film reinforces the notion of memory, collective or individual, and frames it within current discussions of historical memory and history.<sup>12</sup>

Using the same new documentary film techniques as *Bicicleta* and *Voces*, Jordi Solé Tura's life reconstruction is threefold in *Bucarest*: Albert Solé's reconstruction of his own past; the historical reconstruction of Jordi Solé Tura's past; and the historical reconstruction of a whole ideological group, that of those who opposed Franco during and after the Civil War and the dictatorship. This recovery of historical memory of a whole generation of leftists is shown in parallel with Jordi Solé Tura's fight against AD, creating a metaphorical meaning in which Tura's fight against AD becomes the social and political fight against forgetting the crucial role of Spanish leftist politicians in recent Spanish history. From issues of individual memory to a complex concept of history, the viewer is induced to reflect upon the metaphorical narrative presented in the documentary film. AD's forgetting triggers the need to recover the individual and collective past in what seems to be perceived as the only way to

preserve memory and identity. Therefore, biomedical discourse on AD is intertwined with political and social discourses on historical memory and historical forgetting that have been at the centre of political debates in Spain in recent years.

The construction of historical memory and the formation of identity are two parallel and reciprocal processes, in as much as individual memory and collective historical memory construct each other. Memory and forgetting are also interrelated in the sense that memory forgets and is full of silences that need to be reconstructed from the changing needs of the present (Colmeiro 2005: 28). The collective amnesia accorded during the Spanish Transition, as a necessary step towards national reconciliation, greatly influenced the manner in which the current Spanish historical memory is being reconstructed. In *Bucarest* collective historical memory, identified here with individual memory and linked to individual and collective identity issues, is reconstructed through diverse sites of memory which replace a real living memory with a trace of this (Nora 1989: 7). *La Modelo*, Barcelona's jail, where Solé Tura spent his six month sentence as a political prisoner, photos and family films, newspapers, news reels, museums, or the International hymn are all memory traces. These traces serve as the basis of a 'fictional' reconstruction of the past, along with the personal recollections of those who lived it, that is, autobiographical memory. Clearly then, the documentary film becomes a textual space in which notions of history and memory contend through the reconstruction of what is no longer an important part of our lives. If collective memory is the active past that forms our common identity, what is presented in *Bucarest* is not collective memory but simply the history of a silenced group that needs to reconstruct itself in time and space. Albert Sole's documentary film recovers traces of memories, but no actual memories.

## **Conclusions**

If we were to destigmatise Alzheimer's disease, cultural constructions of the disease and their articulation of knowledge and power require being unveiled and explained. All the cultural texts studied here are, from different perspectives, creating a meaning of what AD is and how it should be perceived, acted upon and publicly represented. They embody current debates about AD in different arenas, academic and non-academic, and are agents of change in their aim to counteract the stereotypes present in contemporary Spanish culture and society.

*Bicicleta, cullera, poma, Las voces de la memoria, and Bucarest: la memòria perduda* all embody different discourses on Alzheimer's disease, memory and forgetting through the lens of the new documentary film. They all have a very similar structure and show a tension between their aim to offer a factual representation and the impossibility of doing so, due to the ideological positions they each ultimately adopt. All three offer a focus on the most important health and social issue of our time, with the goal of informing and persuading the viewer to hold a particular opinion or to take some action with regards to this issue. Key themes raised include the financial imperative, ideological issues, the global challenges of AD, the pressure of time and negativity or positivity in the way in which the disease is depicted in the formation of public opinion.

In all these three film documentaries, illness narratives are at centre stage, that is, a person's narrative of how he/she directly or indirectly experiences illness,. Communicating personal experiences is a powerful medium for learning about and understanding others (Garro and Mattingly 2000; Sacks 1998), and therefore become an influential means to change or to perpetuate how Spanish society perceives and reacts to AD. The stigma associated with AD is still a ghostly presence in these filmic texts: hence it can even be argued that this stigma informs them, to the extent that these cultural productions become the space in which personal accounts of illness challenge or adhere to the biomedical discourses of ageing and dementia that have permeated Spanish society through different media. They all seek empathy from the viewer towards Alzheimer's disease, but how they do it and why they do it are questions that the analysis of media representations of AD from an interdisciplinary perspective help to reveal and explain.

## ENDNOTES

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<sup>1</sup> A 2009 Price Water Cooper's study finds that of 322,600 places available, only about 25% are at least co-financed with public money. In addition, not all nursing homes have the capacity to care for people with AD (Anon. 2010).

<sup>2</sup> The average amount of money spent per year by a family caring for a member with AD is €30,000, whilst the Spanish government spend an average of €3,000 per patient that will double in the next two decades. (Anon. 2011b)

<sup>3</sup> *El País* has published more than 1,500 articles on the subject since 2000, and *El Mundo* 1,400.

<sup>4</sup> In this sense, the term Alzheimer has developed into a metaphor set to colloquially designate episodes of forgetfulness or to ironically accuse politicians of political misconduct.

<sup>5</sup> Jordi Solé Tura died in 2009.

<sup>6</sup> The book *Maragall vs Alzheimer* ([Cromosoma ediciones](#)) was published in 2010 and provides a more personal portrait of Maragall's fight against AD. It was written at the same time as the making of the documentary film.

<sup>7</sup> *La pelota vasca* and *Flamenco* are the two top documentary films in the box-office.

<sup>8</sup> The current theoretical debates around the role of fiction, reality, subgenres, etc, are of great interest in their own right. This essay embraces Bruzzi's theoretical approach to new documentary film, and therefore it does not classify the three documentaries within Nichols's

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six types of modes of documentary: expository, poetic, observational, participatory, performative, and reflexive.

<sup>9</sup> All three synopses have been adapted and translated from their original Spanish versions provided by their film distributors

<sup>10</sup> However, in the case of Maragall's documentary film, part of the events—among them diagnosis and first months after diagnosis—are re-enacted

<sup>11</sup> University student music bands that date as far back as the 1215 with King Alfonso X, the Wise.

<sup>12</sup> Jordi Solé Tura, a key player in Spain's transition from dictatorship to democracy, was born in 1930. In the mid-1950s, he joined the Frente de Liberación Popular [Popular Liberation Front] and then, in 1957, the Partido Socialista Unificado de Cataluña [Unified Catalan Socialist Party]. In 1960, he went into exile in Paris and in 1961 he was sent to Bucharest to work as a broadcaster on Radio Pirenaica [Pyrenees Radio ], which broadcast to Spain. In 1964, he left the PSUC, accusing the Partido Comunista Español [ Spanish Communist Party ] of a lack of democracy, returning to Spain and going to found and lead Bandera Roja [ Red Flag ], a student-based Maoist group. An important figure in many struggles against the dictatorship, he was imprisoned in 1969. In 1974 he rejoined the Partido Socialista Unificado de Cataluña but left it in 1985 to join the Partido Socialista - Socialist Party - led by Felipe González. As I have already noted, Solé Tura was one of the seven founding fathers of the Spanish Constitution of 1978.

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