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# The *épreuve* of ageing with Alzheimer's disease

VINCENT CARADEC\* and ALINE CHAMAHIAN\*

## ABSTRACT

The concept of *épreuve*, literally translated as ‘challenge’, was developed by the French sociologist Danilo Martuccelli, who was inspired by Sartre’s existential philosophy, phenomenological sociology and its concern for analysing modern experiences, and Charles Wright Mills’ conviction that it is necessary to relate personal problems to the social structures that generate or amplify them. The concept has been used in the sociology of ageing in France to characterise the *épreuve* of ageing and four domains of *épreuve* have been identified: activities, identity, autonomy and relationship to the world. This paper applies this template to a corpus of 27 interviews with people at mild to moderate stages of Alzheimer’s disease, in order to characterise the *épreuve* of ageing with the disease. The *épreuve* of ageing during the earlier stages of the disease is similar to the experience of people who age without a cognitive disorder. However, as the disease progresses the analysis reveals that it tends to exacerbate issues: identity seems especially threatened, simultaneously raising the question of self-presentation and self-definition; although most interviewees strive to retain autonomy, a few delegate it to a close confidante with whom they build a relationship of strong dependence; and weakened communication accentuates the feeling that the world is foreign and strange.

**KEY WORDS**—Alzheimer’s disease, self-identity, autonomy, communication, challenge.

## Introduction

In France, as in many other countries, Alzheimer’s disease embodies the ‘archetypical figure of “ageing going badly”’ (Ngatcha-Ribert 2012: 7). Following changes in its medical categorisation and through the combined actions of health professionals, the media and families’ associations, Alzheimer’s disease has gradually emerged as a major social issue, leading public authorities to make it a priority concern. In France, for example, Alzheimer’s disease became a major public policy issue in the 2000s,

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leading to the creation of an ‘Alzheimers and related disorders’ plan (2008–2012) that received significant financial support under the presidency of Nicolas Sarkozy.<sup>1</sup>

Alzheimer’s disease’s public exposure was accompanied by the construction of a very sombre imagery. The family and friends of people with Alzheimer’s disease have been described as collateral victims of the illness, weighed down by the ‘burden’ of care (Zarit, Orr and Zarit 1985) and exhausted by the magnitude of the tasks they have to assume. At the same time, people with the disease were seen as having lost the core of their humanity – their memory and ability to reason – condemning them to identity loss and a zombie-like state (Behuniak 2011). More fundamentally, in a ‘hypercognitive’ culture and society that emphasises people’s powers of rational thinking and memory (Post 1995), people suffering from Alzheimer’s disease tend to represent radical alterity. Also, ageing with Alzheimer’s disease is considered to be a form of ageing apart today, in contrast to contemporary norms of ‘active ageing’, ‘successful ageing’ or ‘ageing well’. This negative image of people with Alzheimer’s disease is relatively uniform, since the category of ‘Alzheimer’s sufferer’ tends to obfuscate all differences. People are only considered in terms of their cognitive deficit and are reduced to an attributed illness-based identity, the assumption being that their disease is in an advanced stage.

Of course, these representations are unsatisfactory for the social sciences, which have sought an alternative perspective on the illness through the development of particular methodologies and analytical tools. Methodologically, researchers study the experience of people with Alzheimer’s disease directly through their narratives and accounts in order to understand the lived experience of the illness, and re-situate these experiences in context. Research conducted in the United States of America, the United Kingdom and, more recently, in France has gradually included the long-neglected viewpoint of people with Alzheimer’s disease, at least those in the early stages who are able to speak about their experience (Cotrell and Schulz 1993; Cowdell 2008; Downs 1997). Several studies have explored daily life with the illness (MacRae 2008), how threats to identity are managed (Beard 2004; Clare 2002, 2003), the tension between acceptance and denial (Macquarrie 2005), and the connections between identity maintenance and narrative processes (Bouchard Ryan, Bannister and Anas 2009; Hyden and Örvulv 2009). This research focuses on how people with Alzheimer’s disease confront it and sometimes fight back, ‘making the best you can of it’ or declaring ‘we’ll fight it as long as we can’ (Clare 2002).

In addition to detailed description of the strategies employed, sociological research focusing on the lived experience of people with Alzheimer’s disease has two major strengths. The first is that it shatters the uniform

image of the experience of the illness: Hulko (2009) demonstrates that having Alzheimer's disease may be experienced as a great drama or it may not be, emphasising the variability of an experience 'ranging from "not a big deal" to "hellish"'. Such research also demonstrates the gap between the usual representations of the illness and the actual experience of people afflicted with it, for whom it is not always a disaster, some relativising their difficulties and managing to preserve their identity (Beard 2004; Chamahian and Caradec 2014; Clare 2002; MacRae 2008). The second strength of this approach is that it considers the illness from a perspective other than the physiological. The illness is seen as part of a context that simultaneously provides an interpretive template and the resources for confronting it (Downs 2000; Kitwood 1990; Lyman 1989). This context is first and foremost socio-historical and cultural: depending on the era and culture, cognitive difficulties can be thought of as challenges inherent to ageing whose dramatisation would serve no point, as in China (Lupu 2009), or as symptoms of a specific cognitive pathology requiring diagnosis and treatment, as in western societies today. The context also includes the social background of sufferers, as Hulko (2009: 136) has demonstrated in the observation that Alzheimer's disease is less tolerable among higher social class groups, where identity tends to be formed around cognitive performance. Lifecourse experiences are also part of the context, as shown in Lichtenberg's (2009) observation that African Americans are faced with more risk factors for developing dementia over the course of their lives, especially poor childhood nutrition. Lastly, the extent and quality of the social environment of people with Alzheimer's disease are significant (Chamahian and Caradec 2014; Kitwood and Bredin 1992; Surr 2006).

This paper builds on the sociological perspectives of the research cited above, but in a specific way, since its aim is to examine the *épreuve* (literally translated as 'challenge') of ageing with Alzheimer's disease. The concept of *épreuve* was formulated by French sociologist Danilo Martuccelli, who was inspired by Sartre's existential philosophy, phenomenological sociology and its concern for analysing modern experiences, and Charles Wright Mills' assertion that it is necessary to 'connect personal problems and the social structures that generate or amplify them' (Martuccelli and de Singly 2009: 73). Martuccelli holds that a society can be characterised by the *épreuves* it presents to the individuals composing it, 'historical, socially produced, unequally distributed *épreuves* that individuals are forced to confront' (Martuccelli 2006: 12). This concept has been used by French sociologists of ageing to characterise the *épreuve* of ageing based on research conducted with people without cognitive problems. They have identified four domains of *épreuve*: activities, identity, autonomy and relationship to the world (Caradec 2007). This paper aims to apply this template to

research conducted with people with Alzheimer's disease. It demonstrates how people with Alzheimer's disease experience changes in their relationship to themselves and the world and aims to understand the extent to which their ageing experience differs from that of people without the illness and whether these changes alter the *épreuve* of ageing.

We first introduce the template for analysing the *épreuve* of ageing and its four domains. This is followed by a presentation of our study on the experience of people with Alzheimer's disease. Lastly, we evaluate how well this *épreuve* of ageing template applies to our corpus.

## Background

Over the past 20 years, French sociologists have been influenced by theoretical approaches that give increasing attention to individuals and their experiences (Martuccelli and de Singly 2009), chief among them Berger and Luckmann's constructivism, Schütz's phenomenological psychology, and Beck and Giddens' theories of individualisation. In the field of social gerontology this trend is evident in a body of research aiming to account for the process and experience of individual ageing. Some French scholars have focused on transitions related to ageing, such as retirement or being a widow(er), analysed using the concept of identity (Caradec 2004). Other studies (Barthe, Clément and Drulhe 1988; Clément and Membrado 2010; Mallon 2004) have elaborated the concept of *déprise*, designating the process of converting one's life to overcome or compensate for difficulties linked to the ageing process. More recently, Caradec has proposed gathering prior research contributions under Martuccelli's concept of *épreuve* (Caradec 2007; Martuccelli 2006). Since individuals are forced to confront historically, socially produced and unequally distributed *épreuves*, the concept is thus an analytical operator where the macro- and micro-sociological levels meet: the *épreuves* have both a societal dimension (since it is the social context that gives them form) and an individual dimension (since they are felt by individuals, and differently according to their resources).

This perspective prompts us to argue that contemporary western societies oblige a growing number of individuals to confront a range of challenges by allowing them to reach an increasingly advanced age. These challenges come from physiological changes (health problems, functional limitations, accumulating fatigue) and changes in the social and material environment (the death of peers, family and friends' increased anxiety and attention due to their growing old, a more hostile outside world where older people are considered burdensome and face a variety of forms of ageism). They vary

according to social class, and are part of what could be called the '*épreuve* of ageing', leading to gradual changes in how people reconstruct their identities and relate to the world. These changes can be sorted into four domains, each touching on a central existential issue for ageing: the domain of activities draws attention to the issue of preserving connections with the world; the domain of identity refers to the way that older people try to preserve a feeling of their own worth; the domain of autonomy raises the question of retaining power to decide for oneself; and the domain of the relationship to the world (and its strangeness) broaches the issue of maintaining places familiar to the ageing person. Table 1 presents the *épreuve* of ageing template; we will develop each domain in greater detail in the text that follows.

The first is the domain of everyday activities. Because of the aforementioned challenges, with advancing age it may become difficult to pursue certain activities. Ageing people are consequently in a process of reorganising their lives under an increasing number of constraints, going through a series of adjustments, renunciations and reconversions. As previously mentioned, French sociologists have called this phenomenon *déprise*. Although the French term is reminiscent of disengagement (Cumming and Henry 1961), there are at least four differences between them. Firstly, the theory of *déprise* does not stop with the observation that certain activities are abandoned with the advancement of age, going on to emphasise that some activities are retained, abandoned activities may be replaced by others, and certain activities may be voluntarily set aside in order to 'hold on to' others, following the principle of the 'economy of strength' (Clément and Membrado 2010: 118). Secondly, whereas disengagement was presented as an inevitable process, *déprise* is a probabilist phenomenon that prompts changes in habits which are increasingly likely to appear as age advances, but they may also not arise. Thirdly, *déprise* recognises that individuals have the capacity for action: when confronted with challenges, people deploy strategies according to the extent of their ability to adapt. From this perspective, the concept of *déprise* has a degree of family resemblance with 'selective optimization with compensation' (Baltes and Cartensen 1996), which also emphasises strategies for adapting to ageing. Its aims are wider, though, since it envisages ageing not only in its successes (the ability to adapt to new limitations) but also in its more negative dimensions (giving up activities that the person was very attached to, which could be qualified as the 'ultimate *déprise*' (Clément and Mantovani 1999). Consequently, *déprise* is a socially differentiated process, both because difficulties are unevenly distributed (as data on morbidity and disabilities attest) and because the deployed strategies depend on the resources available to individuals. Fourthly, the theory of *déprise* is not intended to offer a

TABLE 1. *Template of the épreuve of ageing*

Societal dimensions of the <i>épreuve</i>	Individual dimensions of the <i>épreuve</i> : four domains	Key existential issue associated with each domain	Empirical indicators of each domain
With lengthening of life expectancy, a rising number of people reach increasingly advanced ages and are exposed to a range of challenges that come from physiological changes as well as changes in the social and material environment (especially ageism)	Activities	Maintaining connections with the world	Transformations of activities (adjustments, renunciations, reconversions)
	Identity	Preserving a feeling of their own worth	What people say about who they are today, how they are seen by others, how they compare themselves to other (older) people
	Autonomy	Retaining power to decide for oneself	Discourses about the help they receive and their decision-making abilities and difficulties
	Relation to the world (and its strangeness)	Maintaining familiar places	Discourses about their place in the world and how they (mis)understand it

reading of ageing as external to individuals. On the contrary, it leads us to emphasise that one of the major existential issues for older people is continuing meaningful activities as long as possible, or put another way, preserving significant connections with the world.

The second domain is that of identity, the existential issue concerning ageing people's ability to preserve a feeling of social worth, which is likely to be challenged in a variety of ways. Research has shown that there are four aspects to identity in elders. The first is a tension between 'being' and 'having been': the issue is knowing the extent to which self-esteem can still be based on current engagements, or if people have no other solution than to base their social value in the past, in what they used to be and do (Caradec 2004). The second aspect refers to how ageing people manage others' perceptions that reduce them to 'old age': can they manage to distance themselves from this view, or do they let themselves be closed in by it (de Beauvoir 1972; Minichiello, Browne and Kendig 2000)? The third is related to the fact that older people's self-evaluation is also forged by how they compare themselves with others of the same age. From this perspective, the strategy of 'downward contrast', which is the comparison with someone judged to be less good than oneself, is by far the older person's most frequent comparison strategy (Beaumont and Kenealy 2004). Lastly, the fourth concerns the way in which ageing individuals position themselves

in relation to ageing: do they think they are *getting* old, or that they *are* old forever after (Balard 2013; Caradec 2004; Cavalli and Henchoz 2009)?

The third domain concerns the control that ageing people manage (or fail) to keep over their lives. Indeed the prevalence of functional limitations and activity restrictions increases with age (Cambois, Robine and Romieu 2005), as does the risk of frailty or becoming dependent for activities of daily living (Guilley *et al.* 2008; Lalive d'Épinay and Spini 2008). Although we must remember that not all older people have functional limitations, an increasing number of them do need family or professional help to perform certain tasks as they age (shopping, house cleaning, personal care, *etc.*). The issue that arises is the maintenance of their 'decisional autonomy', or their ability to decide their own affairs when their 'autonomy of execution' declines, to use Collopy's (1988) distinction. Existing research stresses that older people struggle to maintain their decisional autonomy, a fundamental value in contemporary western societies. They use a range of strategies to this end: hiding potentially worrying incidents – like falls – from their loved ones so that they will not intervene even more often; rejecting the home assistance social workers planned for them when they do not want them and their intervention chips away at their autonomy (Gucher *et al.* 2011); for those living in a retirement home, protesting instructions about hygiene, food or medication, or refusing to participate in group activities (Mallon 2004: 147–56). We should add that another kind of figure emerges in some studies, albeit one sketched with less precision: people who develop a sort of indifference to things as they age, letting their family or professionals make decisions for them and thus delegating their autonomy (Collopy 1988; Membrado 1999).

The fourth and last domain is that of the relationship with the world. Indeed with advancing age there is a tendency to develop a feeling that the world is strange and foreign: the impression of having an increasingly difficult time understanding the society in which one lives, and being part of it. Older people could thus be thought of as paradigmatic figures of the gap between objective and subjective cultures that Simmel considered to be a major characteristic of modernity (Simmel 1968); put in other terms, they could be seen as 'immigrants in time' (Dowd 1986). Among various statements from interviews or the journals of quite elderly writers (Argoud and Veyssset 1999), we cite an illustrative example from Claude Lévi-Strauss, who at the age of 96 declared, 'we are in a world to which I already no longer belong. The one I knew, the one I loved, had 1.5 billion inhabitants. The current world has 6 billion humans. It's no longer mine'.<sup>2</sup> This difficulty in subscribing to current society is borne of multiple mechanisms. Abandoning activities that make people feel like they are still engaged with the world risks imposing an even greater distance

from it. In parallel, the deaths of peers that lived through the same eras, who ‘could read your mind’ (Clément 2000) and shared a degree of complicity, contribute greatly to this feeling. The same holds true for changes in the environment, such as technological developments or modifications in the urban environment that result in one becoming a stranger in one’s own town or neighbourhood. Faced with this growing foreignness of the world, the existential issue is to maintain parallel familiar spaces. There are two general strategies that stand out. The first consists of fighting this feeling of strangeness, and some people adopt new technologies to be able to ‘stay with it’. The second strategy is to shut oneself into a close space, familiar and safe, that counter-balances the strangeness and insecurity of the outside world: ‘home’.

In conclusion, we emphasise that there are many ways of responding to the existential issues raised by these four domains. When facing the *épreuve* of ageing, resources are unequally distributed along two criteria. One is that resources come from the past, such as financial resources, health more or less preserved depending on the kind of work one did, and abilities to adapt resulting from educational levels and past experiences. The other is that they come from the present environment, which may offer more or less favourable support, be it relational or material, such as transportation and urban facilities.

In sum, the *épreuve* of ageing breaks down into four domains: activities, identity, autonomy and relationship to the world. It is important to remember that these domains have been designated on the basis of research with people without cognitive problems. The question now is whether it applies to people who are ageing with Alzheimer’s disease.

## Methods

Our corpus is composed of 27 interviews conducted with people attending the Memory Consultation Centre at the Regional University Hospital Centre (Centre Hospitalier Régional Universitaire) in Lille, France.<sup>3</sup> There were two criteria for inclusion in the sample. Firstly, we decided to interview only people who had been diagnosed with Alzheimer’s disease and informed of the diagnosis. Consequently, we excluded other forms of neuro-degenerative dementia (vascular, Lewy body, fronto-temporal), since the goal was to assemble a diagnostically homogeneous population in order to be able to explore the variety of experiences. Secondly, our interviewees had to be capable of speaking coherently about their experience. We thus retained people in the ‘mild’ or ‘moderate’ stages of the illness based on their Folstein test scores (Mini-Mental State Examination;

Folstein, Folstein and McHugh 1975) obtained through memory consultations. Most of our interviewees had a score at or superior to 20/30, and a few slightly below 20.

We next diversified the socio-demographic characteristics of our sample. It consisted of 11 women and 16 men, aged 52–92.<sup>4</sup> Nearly all lived at home (although one lived in a religious community and four in retirement homes). The majority of people we met (18) had left their professional activities several years previously, but some (two) were still professionally active and others' (seven) work had been cut short following diagnosis, when they were put on disability benefits or retired. Concerning social positions, people in our corpus were mainly in the middle and upper classes, but just over a third (N=10) were former labourers, basic employees or farmers. Lastly, we paid particular attention to domestic situations: 17 lived with a spouse or partner, six lived alone and four lived with one of their children. Although research was primarily with the ill people themselves, whom we tried to interview alone without family present, when possible we ended meetings by also speaking with a family member (a partner or a child).

Our resolutely qualitative methodological approach is inspired by the Weberian and Schützian traditions aiming to understand and reconstruct the social worlds experienced by individuals. It is an interpretive sociology (Angermüller 2005) in which 'comprehensive' interviews (Kaufmann 2008) are considered as 'an interindividual configuration where one person invites another to speak about a topic whilst effectively recognizing the right to inter-subjectivity, in other words, a right to an independent subjectivity' (Matthey 2005: 5). We contacted people at the memory centre or by telephone, either directly with the person we wished to interview or through a family member. There were no refusals to participate in the study. All but two interviews were conducted at the interviewees' residence, which is a protective setting for their identity (Hellström *et al.* 2007).

The interviews lasted from 30 minutes to three hours, and began with the following statement: 'You have been diagnosed as having Alzheimer's disease. Can you tell me how you experience life with this disease?' This made it possible for us to explore the two main lines of the interview guide. The first one concerns daily life with Alzheimer's disease. Several dimensions were explored: their previous or current occupational career and the effects of diagnosis on its advancement; family life and the nature of ties with relatives around and supporting people with Alzheimer's disease; social life and leisure. Lastly, an emphasis was placed on everyday life and daily tasks (driving, shopping, cleaning, *etc.*). More broadly, we tried to gather a wide-ranging discourse on social representations of the illness and ageing. The second line concerns the disease over time, trying

to understand the history of the illness's development from their first problems up to the interview. We asked about the context of the appearance of their first difficulties, their decision to consult a doctor, the process leading to the diagnosis and the experience of receiving it. We also included questions on identity dynamics through these steps (claims to be ill or not, and in which contexts) and their potential evolution over time. The domains of the *épreuve* of ageing template were not directly addressed, as the idea was to collect discourses on these domains and the related existential issues through narratives on how people lived today and what the disease changed in their lives, but not through direct, leading questions.

Interviews were carefully transcribed then analysed in a two-phase process. In the first phase, each interview was analysed internally to identify its salient points and reconstruct its logic. This internal analysis was conducted both inductively and using a template for analysing the *épreuve* of ageing. Discourses corresponding to each domain of the *épreuve* of ageing were assembled in order to analyse them inductively, allowing the two researchers to discuss the interpretation. In the second phase, we conducted a transversal analysis in which we inserted discourse from all interviews into each of the domains on the *épreuve* of ageing template. In this phase of the analysis we paid particular attention to the variety of postures adopted, which we tried to reconstruct by building ideotypical typologies (Schnapper 1999).

## Findings

We now return to the *épreuve* of ageing's four domains to use them as a template for reading the interviews we conducted. This will show the extent to which this analytical template applies to our corpus and the ways in which it helps shed light on the *épreuve* of ageing with Alzheimer's disease. The results are summarised in Table 2.

### *The domain of everyday activities, between *déprise* and holding on*

In the first domain, we conclude that the *déprise* approach aptly applies to the people in our corpus. They told us how they came to give up activities they could no longer practice or that had been forbidden to them while trying to maintain others. This *déprise* is particularly present in certain kinds of activities.

It is first of all the case for reading, especially books, which becomes gradually more difficult as memory problems worsen. Thus Martine (age 76, former librarian) gave up reading books and contents herself with

TABLE 2. *The épreuve of ageing with Alzheimer's disease*

Societal dimensions of the <i>épreuve</i>	Individual dimensions of the <i>épreuve</i> : four domains and key existential issue associated	Empirical findings
In addition to the challenges of ageing presented in Table 1, there is also the stigma of Alzheimer's disease, which is seen as a loss of essential components of identity: rational thinking and memory	Activities: maintaining connections with the world	<i>Déprise</i> of activities is particularly present in three domains: reading, mobility and communication
	Identity: preserving a feeling of their own worth	People face a double challenge: <ul style="list-style-type: none"> <li>• Managing how one presents oneself to others and the risk of stigmatisation</li> <li>• Reacting to the question of how much the illness is affecting one's identity (with three postures: preserved identity, threatened identity, altered identity)</li> </ul>
	Autonomy: retaining power to decide for oneself	Two positions can be identified: proclaimed autonomy and (radical) delegated autonomy
	Relation to the world (and its strangeness): maintaining familiar places	The issue of communication is a major dimension of the <i>épreuve</i> . Two strategies can be observed: looking for palliative solutions to maintain communication and abandoning customary ways of communicating with others

reading pamphlets of two or three pages, explaining, 'not a whole book, because I don't know what I read at the beginning any more. That's how it is now'. Likewise, Michèle (66 years old, former businesswoman) buys herself little books of very short stories that allow her to continue 'reading stuff', even though it is increasingly difficult for her. Akso Paul (age 59, engineer) no longer reads novels, only technical journals.

*Déprise* next concerns the participants' ability to go from place to place, whether on foot, by public transportation or by car. Indeed these trips become difficult when they lose their sense of orientation or become potentially dangerous behind the wheel. The practical and symbolic importance of this kind of activity has already been demonstrated (Balard 2013; Caradec 2004), and it is a particularly good illustration of how *déprise* is built through interactions with family and health professionals, who may go so far as to force an afflicted person to stop driving. For instance, Lucie (76, former housecleaner) explains why she stopped taking the train:

It's not that I don't want to anymore, it's my head. I asked the doctor if I should go out or anything, if I wanted to go see my granddaughter, but you have to take the train to Paris, and you have to change trains to take another one. And he said no... so it's over, I can't go any more.

Lastly, there is a third area of activities that is especially diminished for the participants: communication. We will address this and give some illustrations in our discussion of the fourth domain, since it also raises the question of the relationship of familiarity study participants have with the world.

Confirming the findings of previous work on *déprise* (Clément and Membrado 2010), the participants use these conversions to do what they can to continue activities that are especially important to them, and which they struggle to keep: running errands; cooking meals; reading (for Martine, cited earlier); writing books (Serge, a former professor, 66 years old, who is hesitant to give lectures because he no longer feels as sure of himself verbally); or taking care of one's animals as one has always done (Albert, a 55-year-old former labourer who lives in the country).

As in other work on *déprise* (Caradec 2007), we also observe the establishment of strategies such as taking notes, making lists or keeping a diary to compensate for memory problems. As we indicated earlier, these strategies depend both on participants' previous trajectories and their available resources. For one thing, they depend on resources accumulated over their lifetimes. For instance, date calendars are familiar objects to some participants who used them in their professional lives or as a newly retired person, while others had never used one, such as Louis, an 80-year-old former farmer, or Roland, a former high-ranking civil servant of 64 whose secretary had always managed his schedule for him. But these strategies also come from the resources available in the present. Paul (59, engineer) was able to keep his job as a local civil servant by taking advantage of a specific illness leave programme and due to his director's particularly understanding attitude. Another example: Daniel's wife bought him (54, former architect) a dog that would subsequently play a central role in his life: it gives him company while his wife is at work and gives a rhythm to his days through regular walks that give him the chance to see the building superintendent and neighbours. We could add that these strategies may be more or less constrained: sometimes there is little flexibility left, as when an ill person is required to stop driving or, for those who are not yet retired, when the employer summarily puts an end to their professional activity.

Although the phenomenon of *déprise* is quite present in the interviews, it is also sometimes difficult to characterise because occasionally the interviewees' speech seems ambivalent or even contradictory about how some of their practices have changed. The entangled and confused speech that runs throughout some interviews can be summed up by two formulations.

The first is, 'I don't do it anymore/I still do it'. Accordingly, Emile (former engineer, 76) – who we know no longer drives – explains that he now lets his wife drive because 'she likes it a lot' while assuring us that 'that doesn't stop me from taking my car and going someplace by myself'. The second formula can be summed up as, 'I don't do it anymore, but I still know how'. In fact, we could consider statements along these lines coherent if we account for two things: firstly, that they typically place different periods of their recent lifecourse into the same temporal frame, and secondly, that interviewees are emphasising skills that they think are preserved, even if they no longer use them, and try to present an identity little affected by the illness.

### *The domain of identity: self-presentation and definition*

The identity issue seems to be essential for our interviewees, as their identities are threatened on two fronts. One is society's view of the illness (Kitwood 1997; Langdon, Eagle and Warner 2007). The participants in our study refuse to be thought of exclusively as 'Alzheimer's sufferers', knowing they are at constant risk of being discredited (Goffman 1963) and reduced to this single characteristic. The other is that their identity is threatened by the cognitive problems affecting them (Clare 2003). The participants wonder how far these problems have advanced and ask themselves what they are still capable of doing and what they are worth, as in the case of Elisabeth, age 83, who doubts herself and wonders if she is still 'up to' her grandchildren. This double threat to identity opens two analytical paths towards self-presentation and self-definition.

We start by examining the first. Diagnosed people like those in our study wonder whether they have to tell people other than their closest family and friends that they have the illness (Beard 2004). There are two general strategies. The first is trying to hide the illness to avoid being discredited. For example, Etienne (69, former engineer) refrains from mentioning his diagnosis to anyone outside his family circle for fear of being considered crazy: 'I avoid talking about it, because people have such a negative connotation, um, of that thing, that they practically take you for, like, a nutter or talk to you like you're, y'know, a child, which I really want to avoid'. This strategy conforms to the observations of Langdon, Eagle and Warner (2007), who have stressed people's reticence to talk about their illness beyond their closest friends and family. In the opposite direction, the second strategy consists of stressing the diagnosis in order to justify certain strange behaviours and to try to limit other people's negative judgement. This is Michèle's (66, former businesswoman) strategy. She explains that 'it's too obvious now ... they [other people] really have to understand. Otherwise they might say,

“but she’s crazy!” Although this strategy seems to be the opposite of the previous one, the goal is similar since it, too, is about keeping her distance from the figure of a crazy person. But in the second case, it seems preferable to be taken for sick than for crazy. The transition from the first to the second of these strategies can moreover be observed when the former no longer seems tenable. This is the case for Alain (71, former doctor), who recounts how he came to tell his bridge partners of his illness:

- Alain: So when I’m in public, like when playing bridge, well, I listen, but I don’t, y’know, talk much, to not show too much that I have memory problems. Not long ago I used to always make like there was nothing, y’know. No, no, it hasn’t been very long since I spoke up about it.
- Interviewer: So actually, how did it get decided to talk about it?
- Alain: Well, when I was forgetting the cards, then ... Well, for that matter, maybe I did it like that. When I forgot cards, uh, I’d say ‘oh, that’s right, I’ve got a...’ or ‘oh, I never remember anything!’, it began with remarks like that, y’know. How it happened exactly, that I couldn’t say anymore (*laughs*).
- Interviewer: Yes (*laughing*).
- Alain: But that’s exactly the problem. Now at least they know.

The second path for analysis opened by the domain of identity is that of self-definition. People with an illness find themselves faced with the question of knowing to what extent their identity is altered by their illness. Clare (2003) suggests that the answers are placed on a continuum between two extremes, running from ‘self-maintaining’ (when people normalise the situation and minimise the difficulties in maintaining continuity with their prior sense of self) to ‘self-adjusting’ (when they confront threats head on and try to integrate changes into the self). In our study, the participants’ discourses led us to distinguish between three postures, which could be called preserved identity, threatened identity and altered identity.

The discourse of preserved identity is that of interviewees who feel that their identity is little affected by the illness. They think that their problems are benign, that they are external to the self, and that they have few consequences on their lives. These minor problems do not change who they are, to the point that some of them even challenge the diagnosis of Alzheimer’s disease. Thus Louise (84, former preschool teacher) was shocked by the diagnosis because it is so far from the image she has of herself, as someone with the memory of an elephant. Today she lives as though the illness did not really concern her: ‘I still have the impression that I don’t really have it ... I don’t know how to put it ... I don’t feel different! I still have my memories, I have everything’.

The second type is threatened identity. The illness has not yet touched the core of identity, but it is more present. What predominates in interviews, then, is worry about how it will develop and its future consequences, as well as the on-going fight to contain its progression through memorisation exercises or participating in therapeutic trials. We cite the example of Serge (65), a former professor specialised in the writer Verlaine, who presents himself as such and who explains that 'so long as I'm still able to do intellectual work, I figure I am not entirely done for'. He still writes, especially as 'it makes the neurons work'. But he fears the future because he knows that his problems will get worse and he has the impression he is in a race against time.

Lastly, the third type is altered identity. In this situation, the interviewees have the feeling that the illness has deeply affected who they are and they emphasise what they have lost (their previous capacities, activities they can no longer pursue, their autonomy), and consequently on the changing of their identity. Here we can cite the case of Michèle, a 66-year-old former businesswoman, who tells us what the illness has changed in her life. She cites everything she can no longer do: she can no longer write, she can barely read anymore, she has no more conversations. She stresses how much she has changed: 'I was worth something, and then ... and then ... I had to decline'.

*The domain of autonomy: between proclaimed autonomy and delegated autonomy*

The basis of Alzheimer's disease is altered cognitive and decision-making functions, and it is thus commonly associated with the loss of decisional autonomy. At earlier stages of the illness, however, the situation seems more complex and varied. In our interviews, the question of autonomy leads to two positions: proclaimed autonomy and delegated autonomy.

First of all, as in research conducted on 'normal' ageing, many of our interviewees try to preserve their autonomy. Some do it with the support of their loved ones, like Paul (59, engineer) who regularly does memory exercises and whose wife endeavours to stimulate his mind so he does not let himself go. She explains that 'when you focus on it, it comes back to you, it's not ... It comes back, even if for a minute he goes "what are we doing this weekend?" and uh, I tell 'im "we already talked about it". So, well, if he forces himself, he knows it. So I also try to not always repeat'. Loved ones, then, have to arrive at what we could call the 'right amount' of support, as Alain (71, former doctor) mentions in speaking of his wife:

- Alain: It's her role that's the hard one, actually, because, knowing when she should intervene, um ... So sometimes she intervenes too quickly, when I'd actually understood.
- Interviewer: It's maybe in anticipation of your problems?
- Alain: Yes, that's it, that's what's not easy for her to judge ... there's a learning curve for accepting the gaps and for the others to adapt, and for us to adapt, too.

This is a good example of what Collopy (1988: 16) called 'positive autonomy', in opposition to a 'negative' view of autonomy that asks for non-interference. Spouses struggle together to enhance the ill person's autonomy. Finding the right balance is an arduous task, however. Serge (65, former professor) captured it well when he explained that he gets irritated 'when my wife repeats what she's already told me ten times ... because it's kind of about pride, y'know – I'm not as far as you think!' Participants' autonomy may also be maintained by the balance of power with friends and family, holding their excessive solicitude at bay in order to limit their tendency to make decisions for them and demonstrate that they can still take care of themselves. Lucie (76, former housecleaner) decided to renovate her kitchen without first discussing it with her children, and although she lets people take her shopping, once she is in the store she wants to do it alone and choose her purchases herself. Protecting one's autonomy from loved ones nevertheless presupposes great vigilance, because it is important to not make a slip that might worry them and lead them to intervene more: Lucie is always very careful to check several times that she has turned off the gas.

Inversely, there are also situations where ill people seem to have renounced their autonomy and left all everyday life decisions to a family member, usually a spouse. In such cases autonomy is delegated to loved ones with whom they voluntarily build ties of dependence. This kind of situation aligns with analyses that, in opposition to a long intellectual tradition claiming the contrary, emphasise that autonomy does not mean independence. It 'cannot be viewed as separate from the relationships within which individuals are embedded' (Hillcoat-Nallétamby 2014: 420) and might be compatible with a situation of care and solicitude (Agich 2003; Holstein, Parks and Waymack 2010; Rigaux 2011). In this regard, delegated autonomy should be recognised as a valid form of autonomy (Collopy 1988). In some cases in our corpus, however, this delegation seems particularly radical, because it is not limited to some areas but touches all aspects of life. It is important to point out that such delegation of autonomy may be accompanied by a certain sense of wellbeing or even an affirmation of the pleasure of being alive. Emile (76, former engineer), who now relies on

his wife, sums up how he experiences his current situation by saying, 'I think I'm happy the way I am'. Charles (82, former accountant) stresses how indispensable his wife's presence is for him, as much emotionally as materially. She and his daughter are the only reasons he has left to live. He is no longer interested in anything, lets his wife make all the decisions and feels happy that way because, he explains, he thinks that 'I've done my share'. This wellbeing expressed by the person delegating his or her autonomy may or may not be shared by his or her spouse (Caradec 2009). Charles' wife feels rather good about the situation because her top priority is keeping her husband by her side, so she prefers seeing him ill to losing him forever. But Emile's wife emphasises her exhaustion from having to manage everything herself without getting the recognition she needs, and expresses her pain in seeing her husband change and become something other than what he was.

*The domain of relationship to the world: the communication question*

The domain of relationship to the world, which is associated with the feeling of foreignness that tends to develop with age, brings us to an essential question concerning people with Alzheimer's disease: communication with others. Indeed, the issue of maintaining a certain familiarity with the world revolves around communication for people with Alzheimer's because the illness tends to complicate both of the fundamental conditions for communication – possessing communication skills (knowing how to listen, remember and express oneself) and having a minimal social life (which presupposes having other people around and being listened to).

The illness affects these two conditions variably, leading us to distinguish three pathways where communication ends up being weakened. In the first case, the difficulties mainly arise from reduced communicational skills when the social setting is favourable. For example, Michèle is still well tolerated by her husband and friends, but she participates less and less in discussions because, as she explains, 'there are conversations that last ... I don't know how long, with everyone and all that. And I don't say anything. I can't because I don't understand anything. I can't say a word'. In the second case, the difficulty lies less in the loss of communicational skills than in the weakness of social relations. Elise (66, former teacher) thus painfully explains that her family and friends have grown distant 'since she's in Alzheimer's' and that she lives in a retirement home, a place where 'people don't talk much', 'that is empty', where 'nothing happens'. Lastly, in the third case, communicational skills are preserved and there is family present, but relations are tense because the ill person

feels like what he or she has to say is no longer legitimate. This kind of conflict-ridden setting is what causes people to close in on themselves. Our interview with Lucie (76, former housecleaner) thus illustrates a communicational situation marked by great tension that obliges her to evaluate constantly whether she can risk speaking up: 'I pay attention. When I want to say something, sometimes it works, sometimes it doesn't. Well then, I say, I get it, next time I won't say anything, period, and that's that'. Faced with these difficulties, people with Alzheimer's disease implement a variety of strategies that can be grouped into two clusters: looking for palliative solutions to maintain communication and abandoning customary ways of communicating with others.

The first strategy consists of trying to maintain communication by using a variety of resources to make it possible to pursue conversations and 'save face' (Goffman 1967). These resources may be material objects, which play the role of memory supports and facilitate conversation. Over the course of our interviews, for example, one interviewee took recourse to a digital tablet with images that helped back up what he was saying, and another went to get a product label to be able to give its name. It may also be a matter of mobilising what Goffman called 'safe supplies' (Goffman 1953: 206–16), by developing clichéd comments on the passage of time or urging the interviewer on with expressions like 'onward! next!' in order to hide his or her inability to continue with what he or she had been saying, to give a couple examples. Still other resources come from the past, interviewees using that which is the most accessible to them in their memories. Louis (80, former farmer) thus enjoys talking about the past with his sister, distancing himself from the memory problems that are particularly associated with recent events: 'We talk about the past, we understand the past, we remember it (*laughs*). But the present, there, these machines, these new things that kind of lose us, we didn't learn soon enough'. Lastly, it is also possible to fall back on humour to manage a disphoric interaction situation, disrupted by strange behaviour or speech (Goffman 1953: 259–72). A dash of humour thus allows someone to save face and put the conversation back on course while shifting the awkwardness to other participants. This is what Martine (76, retired librarian) tells us: 'I don't like it when people make unpleasant comments to me ... So, um, in cases like that I laugh and say "well sure, that's how it is, I'm the village idiot!" Then people are a little ... bothered, of course. They are uncomfortable'.

The second strategy consists of abandoning the usual ways of communicating with others. Some speak little, or even withdraw from conversations they can no longer follow (like Michèle, cited earlier), thus making it necessary to find less-demanding or especially tolerant conversational partners.

So it is that Daniel (54, former architect) sometimes slips away from the adult table during large family meals to take refuge with the children to shelter himself from being present for conversations making him feel like a stranger. Also Philippe's wife remarks on her husband's painting teacher's skill communicating with him (57, former labourer) when even she has the feeling she cannot get 'through his bubble':

She has a way of talking with him. Like, he's not stressed, I'll say. Sometimes he makes mistakes in his pictures, I am almost watching what he's doing because I'm afraid that he doesn't know, while the teacher is super cool with him and always tells him in a funny way, so he laughs, even if he forgot ... He takes it well, basically, something that sometimes, with us, he doesn't take so well.

It could also be favouring interactions with animals, which prove to be more readily accessible than people and do not challenge failing relational skills. The relationship between Daniel and the dog his wife gave him is revealing on this point. The dog, which as we saw earlier has a major role in keeping him occupied in daily life, is also a precious resource for maintaining a degree of communication and a space for speaking, since Daniel has some problems in this regard. Throughout the interview he struggles to find words and organise his thoughts, but he seems much more self-confident when he interacts with his dog. The interview was constantly interrupted by the orders he gave his dog: 'What are you doing?', 'To the rug!', 'Sit and stay!', 'We don't run around in circles by the television!' The dog seems to be his favoured interlocutor, much more than the interviewer – 'a companion', he says, attentive and possible to communicate with: 'you have the impression that he understands ... I talk to him, he tries to talk, too'. We should also point out that such undemanding partners in interaction also include technological devices like television or radio, which speak without expecting a response.

## **Discussion and conclusion**

This paper applied the concept of the *épreuve* of ageing to people at a mild or moderate stage of Alzheimer's disease. The concept of *épreuve* has the benefit of articulating the macro- and micro-sociological levels. While *épreuves* are socially produced and vary from one country to the next, the concept is an invitation to study how people face them. It then leads to the emphasis of key existential issues for people in their home society.

When applied to the field of ageing in French sociology, this approach leads to the elaboration of a template of the *épreuve* of ageing, which is an

attempt to think ageing otherwise than through the lens of decline or successful ageing. The template differentiates four domains (activities, identity, autonomy and relationship to the world) and highlights four associated existential issues: maintaining connections with the world, social value, autonomy and familiar spaces in the world. It was developed based on research with older people, most of them over the age of 80 and thus in ‘the fourth age’ (Lalive d’Epinay and Cavalli 2013; Lloyd *et al.* 2014). These studies were based on semi-structured interviews with people without cognitive problems, although we cannot exclude the possibility that some may have slipped into the sample. This analytical template is thus valid in the field of so-called ‘normal’ ageing, since it excluded people experiencing what might be referred to as ‘pathological’ ageing. Hence, this raises the question of whether it might be applicable to people at a mild or moderate stage of Alzheimer’s disease, thus shedding light on the *épreuve* of ageing with the disease.

The domain of activities shows few differences from findings of previous studies on ‘normal’ ageing. Some areas of activity are more affected, especially reading, getting around and communication. As for the issue of identity, the situation seems worse because the illness presents a double challenge: managing how one presents oneself to others and the risk of being stigmatised, and reacting to the question of how much the illness is affecting one’s identity (is it preserved, threatened or altered?) In the domain of autonomy, our study supports previous findings emphasising that ageing people struggle to maintain their autonomy, but it also fleshes out the existence of a situation that is only roughly outlined in work on ‘normal’ ageing: autonomy delegated to a loved one, in a relationship characterised by heavy dependence. Lastly, the domain of the relationship to the world reveals a major aspect of the experience of ageing with Alzheimer’s disease – weakening communication – which can lead people with Alzheimer’s disease to limit challenging interactional situations and to take refuge in their inner worlds. They thus construct a form of strangeness with the world that is more radical than what is observed in other research on ageing.

The research presented in this paper demonstrates that ageing with Alzheimer’s disease does have its specificities. For all that, interviews with people at a mild or moderate stage of the illness do have points in common with interviews in studies of ‘normal’ ageing. We have seen that the *épreuve*-of-ageing model described how ageing people confront a range of challenges that are more frequent with age: health problems, functional limitations, the deaths of their peers, their loved ones’ worry, ageism. In fact, Alzheimer’s disease appears as one of these challenges and, at least at the outset of the disease, people affected by it deal with it as other ageing

people confront their problems: by using the resources at their disposal and implementing strategies to adapt to it and by maintaining their sense of self through perseverance (Lloyd *et al.* 2014). From this perspective, the experience of ageing in earlier stages of Alzheimer's disease is not a radically different form of the *épreuve* of ageing. Instead it exacerbates issues – at least until the moment when communication becomes difficult and the tools of phenomenological sociology become powerless for analysing what is happening.

This research also more generally urges us to think about the role of age in the ageing process. In the model of the *épreuve* of ageing that we presented here, age itself is not put into question, but rather the fact of being confronted with difficulties that are increasingly likely to appear with advancing age. From this point of view, our corpus contains several 'young' sufferers who were diagnosed before the age of 60. They could be thought of as experiencing a sort of early ageing, as they face problems that usually appear later in life. The results are therefore an invitation to enlarge the study of ageing by comparing people at different life stages who are confronted by the same challenges (Chamahian and Lefrançois 2012).

The analytical template has proved to be valuable for analysing the interviews in our corpus. The four retained domains and the four associated issues were a useful framework for describing what comprises ageing with Alzheimer's disease in a society where there is a dark imaginary about this disease which is viewed as a stigma. This template also allowed us to identify the diversity of experiences of people who, from a medical point of view, present a similar profile. The *épreuve* of ageing template therefore looks promising for analysing and comparing other situations of ageing, for example the ageing of people with other diseases, such as cancer, or the ageing of people with disabilities, or at the opposite the ageing of people reaching 90 or 100 with no disease, and for asking what is specific and what is common in these experiences. As the challenges are not the same, we can assume that *déprise* takes different forms and that identity, autonomy and relations to the world are not affected in the same way, but that there is a common endeavour to cling to what is important in life and to preserve a sense of self. The template is also promising for analysing ageing in different geographical areas and in different relational contexts, and for asking how material and relational environment impact the different dimensions of the *épreuve*. In particular, the *épreuve* of ageing could be studied more specifically for people who age with no close family, since relationships with close family appear so important. More broadly, the concept of *épreuve* could be applied

to some specific moments in the ageing process, such as retirement, with the possibility of a comparison between different countries, since it allows one to connect how people live the transition with both their social resources and the conditions of retirement in their country (age of retirement, amount of pension income, incentive to continue working).

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## NOTES

- 1 See <http://www.plan-alzheimer.gouv.fr/> [Accessed 2 February 2016].
- 2 *Le Monde*, 22 February 2005.
- 3 This study was authorised by the CPP (Comité de Protection des Personnes; Committee for the Protection of People) Nord-Ouest III in March 2012 (CPP reference code A12-Do5-VOL12) and the CCTIRS (Comité consultatif sur le traitement de l'information en matière de recherche dans le domaine de la santé; Consulting Committee on the Treatment of Information Related to Research in the Health Domain) in June 2012 (file number 12.328).
- 4 About ten interviewees are thus counted in the category of 'young sufferers', defined as having been diagnosed under the age of 60 (note that this threshold is unique to France and is usually set at 65 years elsewhere).

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