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## Tense Prescriptions? Alzheimer Medications and the Anthropology of Uncertainty

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**Abstract** This article discusses the two major groups of Alzheimer medications, which are hotly debated in the specialized literature because of their doubtful efficacy. Examining this issue under the rubric of an 'anthropology of uncertainty,' this article seeks to address the question: how do doctors prescribe medications given tensions created by uncertainty? A partial answer is drawn from research conducted in Brazil with local psychogeriatricians, which has documented a high degree of certainty regarding Alzheimer drugs and their benefits. I argue that one reason for this certainty is that 'efficacy' has become increasingly non-specific in Alzheimer's disease through the broadening of outcome measures in clinical trials. While such measures previously focused on cognitive symptoms, they now encompass concepts such as functionality, quality of life and activities of daily living. The certainty of the Brazilian psychogeriatricians is further buttressed by three interacting elements: (i) the influence of the pharmaceutical industry; (ii) long-standing arguments for including non-cognitive symptoms in dementia care and research; and (iii) a specific discourse found in geriatrics and gerontology, which recognizes 'the person beyond cognition.'

**Key words** Alzheimer medications • anthropology of uncertainty • efficacy

### INTRODUCTION

Doctors currently prescribing Alzheimer medications are often confronted with two contradictory messages. One is that the more recent drugs

represent advancements in efficacy and safety; the other is that Alzheimer medications may not work and may even cause harm. In the most general terms, this paper asks how and why doctors prescribe medications fraught with such uncertainty regarding their effects. More specifically, this article looks at doctors prescribing Alzheimer medications in urban Brazil, where the medical category 'Alzheimer's disease,' the most common form of a dementia, has penetrated public awareness only relatively recently (in the mid-1990s).<sup>1</sup>

Alzheimer medications can be divided into two major groups: (i) cognitive enhancers, drugs acting on the 'forgetful brain'; and (ii) psychiatric medications, targeting mainly behavioral and psychological symptoms of dementia, such as sleeping problems, depression, and hallucinations. Since cognitive decline is the central symptom of all dementias, the cognitive enhancers are considered the 'real' intervention for Alzheimer's disease. However, the ways in which both medication groups are conceived have gone through major changes recently, as a result of which these two groups are no longer mutually exclusive (see Leibing, *in press*; Leibing, Coignard-Friedman, & Scheinkman, 2006). For example, cognitive enhancers are now also used to treat behavioral symptoms of dementia (e.g. Miller, 2007).

Cognitive symptoms have been targeted by a specific pharmacological treatment since 1993, when tacrine (Cognex) entered the market. Tacrine was a major source of hope; it offered a limited improvement for some (but not all) persons with dementia at a high cost,<sup>2</sup> as it often caused severe side effects. It is no longer prescribed because of these drawbacks, but even today, when other, better tolerated drugs for dementia's cognitive symptoms are available – there are four at the moment on the global market (for an overview see Alzheimer's Disease Research Center [ADRC], 2006) – some researchers deny that any drug of this class is either efficacious or cost-effective (e.g., Harvard Mental Health Letter, 2004; National Institute for Clinical Excellence [NICE], 2001, 2005; Royall, 2005; Trinh, Hoblyn, Mohanty, & Yaffe, 2003,). Conversely, other researchers, many of whom are sponsored by the pharmaceutical industry (cf. Harvard Mental Health Letter, 2004),<sup>3</sup> declare that these newer drugs represent a statistically significant improvement for dementia patients: there seems to be no doubt that some people improve with these medications. Nevertheless, it sometimes remains unclear what type of improvement, exactly, is being measured.<sup>4</sup>

The drugs of the second group, used to reduce behavioral and psychological symptoms, were originally put on the market for adult psychiatric illnesses. Although treating depression in dementia with pharmaceuticals seems to result in relatively good outcomes (e.g., Petrovic, De Paepe, & van Bortel, 2005), the treatment of other behavioral or psychological

symptoms with pharmaceuticals often causes severe side effects such as increased confusion and apathy. In some cases the treatment is simply ineffective (e.g., Sink, Holden, & Yaffe, 2005; Treloar, Beck, & Paton, 2001). The side effects of the traditional antipsychotics are the subject of intense debate within the medical literature, and this is the main reason for the marketing of the newer, pricier atypical antipsychotics.<sup>5</sup> The latter, however, have also recently come under attack, because atypical antipsychotics have 'their "own" adverse effects' (Van Melick, 2004; see also Gill et al., 2005). In fact, the FDA specifically warned that atypical antipsychotics are not recommended for behavioral and psychological symptoms of dementia (BPSD) and can be lethal (see Lenzer, 2005). 'Ironically,' comment psychiatrists Peter Rabins and Constantine Lyketsos (2005, 1964), 'it was only because pharmaceutical companies were seeking an expansion of approved indications for antipsychotic drug use in dementia . . . that the risks came to widespread attention.' In addition, a recent study found that atypical antipsychotics are no more effective than certain older ones (Lieberman et al., 2005).<sup>6</sup>

Brazilian psychogeriatricians (psychiatrists, neurologists)<sup>7</sup> in large urban centers are generally well informed about recent trends in their speciality. Psychogeriatrics has gained a certain importance in Brazil over the last twenty years, as has the topic of aging in general (Leibing, 2005).<sup>8</sup> As everywhere, in Brazil there are a number of leading knowledge producers. These researchers translate and adapt international information for their local colleagues and – with the help of the big pharma enterprises, which invest heavily into Latin America's second largest market (after Mexico) – are responsible for a major part of the training and other forms of knowledge production in psychogeriatrics.

The research for this article was conducted between 2005 and 2007 in the state of Rio de Janeiro, which has the highest percentage of older persons in Brazil.<sup>9</sup> It was around the year 2005 that the 'uncertainty' of both types of dementia medications started to make scientific headlines. Regarding the cognitive enhancers, the evidence-based Cochrane reviews – important vectors of certainty in the medical milieu – were ambiguous, finding both evidence of efficacy (e.g., 'the clinical efficacy [of donepezil] is confirmed'; Birks & Harvey, 2003), but remaining cautious when describing the importance of this effect on patients (e.g., Birks, 2005).<sup>10</sup> In spite of the substantial sea of doubt regarding Alzheimer medications in the specialized, international milieu – which also includes large islands of certainty – the efficacy of Alzheimer medications was never explicitly questioned by the Brazilian psychogeriatricians during interviews.<sup>11</sup>

The following reflections are intended as part of an 'anthropology of uncertainty,' that is, a framework that focuses on the cultural negotiations of certainty and which considers uncertainty, ambivalence, and doubt

powerful transformative social forces. In the specific case of Alzheimer medications in Brazil, this framework facilitates an analysis of the inter-relationship of local practices and the global flux of knowledge on aging, brain, and mental health.<sup>12</sup>

### AN ANTHROPOLOGY OF UNCERTAINTY

Medicine is a science of uncertainty and an art of probability.

(William Osler)

Why might (un)certainty (and related notions) provide a useful framework for thinking about medications?

First, the prescription of medications – the central object in most medical encounters – has been increasingly discussed as an issue of doubt. One position is that the marketing of drugs is driven by economic, rather than clinical, needs. The scandals surrounding Vioxx and hormone replacement therapy are only two examples of recent public outrage concerning profit-oriented health interventions. Such scandals contribute to an atmosphere of unease and doubt regarding medications in general. Authors like Marcia Angell (2000) and David Healy (2006), as well as major newspapers such as the *New York Times*, regularly draw attention to the many, increasingly subtle interventions of pharmaceutical enterprises, ranging from hiding negative data and selectively publishing articles favorable to their products, to providing continuing education to health professionals. Furthermore, in some cultures, patients increasingly reject the prescription of biomedical drugs medications as toxic and unnatural (cf. Whyte, van der Geest, & Hardon, 2002, Ch. 5).

Second, psychiatry (including the overlapping field of psychogeriatrics) can be described as a discipline ‘in search of certainty’ (Rose, 2005). As historian of medicine Janet Tighe (1997, p. 208) writes, ‘no medical specialist’s ability to diagnose accurately has been so persistently and publicly challenged as that of American psychiatrists. Such challenges have been aimed at both the individual physician and the discipline as a whole . . . and have consisted of limited critiques of specific disease concepts as well as broad denunciations of psychiatry’s legitimacy as a scientific medical speciality.’<sup>13</sup> Psychiatry is also the medical specialty in which medications have the highest placebo rate. For example, 50–75% of the efficacy of antidepressant medication is ascribed to the placebo effect (Healy, personal communication; Leuchter, Cook, Witte, Morgan, & Abrams, 2002). While the placebo effect is also efficacious, as Ayo Wahlberg (2008) argues so compellingly, the discourse surrounding this phenomenon reflects profound uncertainty regarding what ‘effect’ means precisely and what medications do, or should do, to people.

And third, some authors have described late modern times as uncertain in general. This description often foregrounds an individual overwhelmed by increasing self-responsibility and decision-making in a context of accruing choice and risk, a situation which is also true in medicine (see Leibing, 2008a). Medical sociologists and anthropologists have repeatedly chronicled how, from the 1950s onward, a distrust of doctors has, in many societies, increased concurrently with patients' growing self-reliance in regard to gathering health information (see Betz & O'Connell, 2003; Leibing, 2008b).

In the social sciences literature, doubt, ambivalence, and uncertainty are often discussed in terms of risk or a need for classificatory action.<sup>14</sup> Some authors argue that uncertainty leads to a reflexive practice. Reflexivity as a means of resisting dominant ideologies has been deemed a positive outcome of doubt by Zygmunt Bauman (1995) and Ulrich Beck (1997), who describe late modern times as 'times of ambivalence'.<sup>15</sup> However, as I will argue, an ethnographic approach to uncertainty, challenges such arguments by allowing us to examine the distinction between the articulation of certainty and its enactment in practice. On the discursive level, certainty may prevail, while practice might be steeped in ambivalence – or *vice versa*: doubt and reflexivity are not necessarily directly linked. For example, as I describe below, doctors often switch their patients from one Alzheimer medication to another, assuring the patient and themselves that the medications work. Some of these doctors know about the literature casting doubt on the efficacy of Alzheimer medications but nevertheless they articulate the general positive effect they had observed in their patients. The transformative power of doubt sometimes lies in the shadows (see Leibing, 2007), involving 'unconscious games' (Bursztajn, Feinbloom, Hamm, & Brodsky, 2000), and there is no imperative that transformation and reflexivity always occur in congruence with 'conscientization,' to use Paulo Freire's term. In fact, as Murray Last (2007) has argued, not knowing and not caring to know can be an institutionalized part of a medical culture. In this case, uncertainty ('I don't know') loses its reflexive powers as it has become one of the everyday practices people simply carry out and are not able, or do not care, to explain.

An in-depth study of certainty and uncertainty – in both narrative and practice – brings together many discussions that one might cumulatively call 'an anthropology of uncertainty'. At issue in these 'narratives of unease' (Kerr, Cunningham-Burley, & Tutton, 2007) is the making of expertise, authority, trust and choice. In the context of medications, one important way to explore the making of certainty is to carefully juxtapose histories of medicines and disorders.<sup>16</sup> With Alzheimer medications, as with many other drugs, at stake is a 'therapeutic embrace,' a term coined by Jeremy

Greene (2007, p. ix) to express how ‘both drug and disease came to alter each other’.

A second, related pathway for exploring the making of certainty is to ask how specialists, in this case psychogeriatricians, gather knowledge through literature, conferences, Internet searches, continued education, informal exchange with colleagues, and the media and integrate this knowledge into their practice. Studies like the one undertaken by Prosser and Walley (2006) show the highly complex process of knowledge gathering regarding new drugs and the problems of constructing one’s knowledge on the foundation of evidence-based medicine.

A third way of thinking through the issue of *uncertainty* is by exploring medical discourse and praxis and the differences between the two. Tacit knowledge, often unconscious and therefore not articulated in interviews, may be revealed through observation. In the case of the research undertaken in Brazil, the declared certainty related to the efficacy of Alzheimer medications contrasted with subtle forms of uncertainty observed in the doctors’ practice.

This article explores a part of the first approach, that of carefully juxtaposing the histories of medication and disease; a separate article will address the other two approaches. However, because even the partial analysis presented here is complex and multilayered, I will focus on one central history, which I consider crucial to an account of why psychogeriatricians in Brazil (and elsewhere) have so readily accepted recent changes in biomedical understandings of Alzheimer medications: the emergence, rise and fall, of the category BPSD (behavioral and psychological symptoms of dementia).

### TREATING ALZHEIMER’S DISEASE IN RIO DE JANEIRO

Brazil’s senior population is growing so rapidly that estimates predict that Brazil will have the sixth largest percentage of elderly worldwide by 2025. Although there is only one geriatrician for every 37,000 Brazilians, geriatrics and related fields are increasingly the specialization of choice among medical doctors (Garcez-Leme, Leme, & Espino, 2005). While leading Brazilian psychiatrists published on the topic of old age as early as the beginning of the last century, the ‘new wave’ of geriatric psychiatry dates from the 1960s and became an important medical specialty only in the 1980s (Piccini, 2002).

Brazilian health professionals are not passive recipients of internationally circulating knowledge. Particularly since the Brazilian psychiatrist Jorge Alberto Costa e Silva became the director of the WHO Mental Health Division – he preceded the current director, Benedetto Saraceno – old age psychiatry developed a strong profile in Brazil and

more Brazilians have become actively involved in the production of psychogeriatric knowledge.

In Brazil, the prescription of geriatric medications is often embedded in or linked to multidisciplinary interventions. This can be partly explained by the fact that Brazilian geriatric medicine is organized by the Brazilian Society for Geriatrics and Gerontology (SBGG). The fusion of geriatrics with gerontology, which occurred in 1969, made 'holistic' and multidisciplinary care the norm (see Achenbaum, 1995, on gerontology's multidisciplinaryity). Nevertheless, while the SBGG was able to accommodate the majority of Brazilian health professionals working with older people, it was also boycotted ('snobbed') by some health professionals who considered the SBGG 'too soft' in its approach towards the basic sciences of psychiatry and neurology. These critics were often the leading knowledge producers in the country and, most of the time, were respected and quoted by SBGG members.

In our interviews, we asked physicians to specifically address the differences between public and private health care settings. It is important to note that it is very common in Brazil for doctors to work in both public and private institutions. In the public healthcare settings, only one Alzheimer medication, Exelon (rivestigmine), is available. When I carried out my research in Rio de Janeiro, Exelon was distributed at only one government pharmacy in the downtown area – and only then after the family filled out complicated paperwork, an often insurmountable obstacle for illiterate people.

In the following interviews regarding treatments for dementia, almost all interviewees spoke of multiple therapeutic interventions. This provides an interesting background for the discussion of recent changes in dementia care, namely the new focus on behavioral and psychological symptoms (BPSD). What unites all of these interventions is that their stated purpose goes beyond addressing cognitive aspects of dementia. In their narratives, the doctors' central preoccupation is invariably the re-establishment of the patient's daily life by emphasizing quality of life, activities of daily living, and functionality.

## METHODOLOGY

Semi-structured, in-depth interviews ( $n = 25$ ) were undertaken with doctors in Rio de Janeiro who described themselves as 'up to date' in the treatment of dementia (through reading articles, participation at conferences, etc.) and who were treating patients suffering from a dementia. Most of the participants were contacted directly or via snowball sampling through a psychogeriatric unit that is part of the Institute of Psychiatry (IPUB-UFRJ) in Rio de Janeiro. Other participants were approached



during the 4th Congress of Geriatrics and Gerontology of the State of Rio de Janeiro in 2006. The interviews were mostly conducted in 2005–2006, with the last four interviews conducted in 2007. The interviews lasted between 25 minutes and 90 minutes and, after giving consent, the doctors explained what they thought about both groups of Alzheimer medications following three lines of questioning: (1) What did the professional think had changed concerning Alzheimer's disease over the last 10 years? (2a) How do they treat people with Alzheimer's disease? (2b) Is there a difference between public and private treatment? and, (3) Where did they obtain their specialization in psychogeriatrics and/or how they have educated themselves in this specialization? All interviews were tape-recorded and transcribed verbatim.

### TENSE PRESCRIPTIONS? THE INTERVIEW RESPONSES

In their answers, the psychogeriatricians showed little doubt in regard to their treatment of dementia, and reflected none of the tension that surrounds the contradictory information about medications, particularly cognitive enhancers. In response to the first line of questioning, most interviewees agreed that things had changed over the last decade. Typical answers included those of a female geriatrician in her mid-30s, interviewed in 2005 (no. 2), a male psychiatrist in his late 40s, interviewed in 2005 (no. 19), a 30-year-old female geriatrician, interviewed in 2006 (no. 18) and a female psychiatrist in her late 40s, interviewed in 2005 (no. 20):

... I know that there is still a long way to go, but we now have access to all updates about inter- and multidisciplinary care, so that patients are handled with more efficacy. Medical technologies have advanced immensely. The choice in pharmaceuticals for treatment and symptom control is growing all the time. And I have to emphasize also the non-pharmacological interventions, which are extremely important ... The goal is to maintain a certain functional capacity and to slow down the progression of the disease. (no. 2)

Not the way of doing the diagnosis, that is still the same, but the understanding of the disease has changed. Before the principal thing for the diagnosis was the cognitive decline and people only looked at memory in a quantitative way. And all the research ... well the research in pharmacology also changed in a way that they pay more attention to things that before were secondary to Alzheimer's disease ... things like activities of daily living, behavioral problems, costs of the disease, the repercussion on the caregiver's health – all that became criteria for the disease and for its gravity ... Yes, now we have medications, which are working; that has been clearly shown. Fifteen years ago we made the diagnosis and had some things to say to the family, certain attitudes towards the patient – but we knew that nothing really could be done. Now you have a group of patients who

respond to the medications . . . Yes, there are groups, not all respond, but some – they really do . . . Well, I think that each medication has certain characteristics and when you know these clinical characteristics of each, the efficacy is comparable . . . (no. 19)

While all interviewees said that the choice and effectiveness of cognitive enhancers for Alzheimer's disease had grown considerably, doctor no. 19 added that the notion of dementia itself had changed, as non-cognitive symptoms had become core symptoms. This quote also shows that while non-cognitive symptoms have long been treated, this was not considered 'the real treatment' prior to the recent, enlarged definition of dementia. While the other interviewees did not explicitly state this, their discourse showed that they too had internalized the new focus on non-cognitive symptoms and notions like quality of life or functionality (*'The goal is to maintain a certain functional capacity'*). In contrast with analogous interviews undertaken in the 1990s, when doctors described their interventions on the level of 'quality of life' as secondary because 'nothing else can be done' (Leibing, 2000), these recent interviews show that notions like quality of life and functionality have become part of the dementia syndrome and a primary target of the treatment plan.

When the physicians were asked how exactly they chose among the available cognitive enhancers, most answered in a similar way, emphasizing the amount of information received concerning the medications and the social class of the patient.

You give the medications to everybody until you find one that works for that person. You can then observe a stabilization of the patient for one, two or three years and afterwards a slower decline when compared to patients without medications or to those with medications, but which do not work. (no. 19)

My criteria are: first of all, the stage of the disease; then comorbidity, the cognitive area which is most affected, international information available about that drug, side effects, costs, and posological simplicity. I prescribe mostly three medications: rivastigmine (Exelon, cognitive enhancer), risperidona (Risperidone, atypical antipsychotic), and citalopram (Citalopram, antidepressant). They are approved by the Ministry of Health, and they had the highest number of clinical tests and they can also be used by poorer people, because they are available at the public services. (no. 2)

My most important criterion is socio-economic. These medications [cognitive enhancers] are quite expensive and not accessible to the poorer people. Afterwards I evaluate the side effects. And finally, if the person with the disease has someone to help her or him to take the medication correctly, so it won't be forgotten. Every patient is different. The only difference is that poorer people have the choice [*sic*] of only one medication, but the clinical treatment is the same for everybody. (no. 18)

There seems to be no doubt about the efficacy of the cognitive enhancers, *once* one has found the right one for a particular patient. A female psychiatrist stated:

The family tells me about the efficacy. They observe that the person is getting more independent, more active, more connected with things out there, more active in family life. One lady, for example, who started the [cognitive enhancer] medication, she went back to reading the newspaper, reading magazines, things she had stopped doing. Another one told me that she went back to watching the soap opera she liked . . . (no. 20)

Most doctors explained the difference between private and public treatment in terms of the number of medications available (more in private), as well as in the number of disciplines involved in the care (more in public):

Yes, there is a difference between private and public treatment. Since one has to make the diagnosis of Alzheimer's by exclusion, a private clinic has more facilities than a public service. As a result, the treatment happens earlier for people who can afford the private. And they have easier access to specialized and well-trained professionals. But there is an interesting aspect – once we have the diagnosis, sometimes the non-pharmacological treatment is much better, richer in public services, because more professionals are involved and more elaborate spaces are available – these are costs which are almost prohibitive for a private clinic. (no. 2)

In short, most interviewees gave a variation of the following statements: (i) In Brazil, the attention paid to the dementias has increased immensely, as has the choice in effective treatments. (ii) Doubts regarding the medications are not doubts about efficacy, but about the suitability of the medication for a given patient. Given the heterogeneity of medications and of patients, the best choice of medication is not always initially clear in a medical encounter. Nevertheless, by switching among medications, an effective treatment can be found. This process is an (internationally) accepted means of prescribing Alzheimer medications (cf. Gauthier, 2002) and does not affect physicians' certainty that theirs' is the right course of action. (iii) Poorer people are prescribed Exelon, although it might not be always the best choice. Wealthier people can have different medications prescribed. (iv) Cognition is no longer the only target of cognitive enhancers.

The reader may notice that doctor no. 19 had more specific knowledge compared to the other doctors quoted. As an academic psychiatrist he is actively involved in the production of psychogeriatric knowledge in Brazil. Interestingly, in his case, his greater knowledge did not lead to more doubt. Unlike doctors no. 2, 18 and 20, he was aware of the current changes in psychogeriatrics that foreground symptoms other than cognition in

dementia. For him, this trend is a conceptual refinement highlighting the efficacy of cognitive enhancers. Neither did he question the second group of Alzheimer medications, most specifically antipsychotics; he described these medications as valuable instruments for helping people with dementia adjust to leading, for some time, an active life:

[Atypical] antipsychotics – we use them a lot, they are first-line treatments. Yes, side effects are observed, but they are monitored, we examine people, all necessary exams and if necessary, we take them off, right? But this is not in all patients. It is around 5 to 10% who have these side effects. If the patient destroys everything, has a delirium, thinks that people steal from him, cannot sleep – and then you won't do anything? One has to do something! The question is not if there are unwanted side effects or not, the question is if you know how to control them – all these medications have side effects. (no. 19)

These interviews show that, at least on the discursive level, between 2005 and 2007 psychogeriatric health professionals in Rio de Janeiro did not doubt the benefits of Alzheimer medications. It is also remarkable to hear that, with the exception of doctor no. 19, non-pharmacological interventions are emphasized as treatment—a strikingly difference from doctors' thinking 10 years ago (Leibing, 2000). However, these non-pharmacological interventions, did not cast any doubt onto the central role pharmaceuticals play in treating Alzheimer's disease. For example, doctor no. 20, who is also a psychoanalyst, has an empathetic approach to patients. She emphasized the 'holistic' part of geriatrics, including nutrition, education, and social factors in patient care more than did other interviewees. She also criticized doctor no. 19 for his overly biomedical approach to psychiatry. Nevertheless, at no point in the interview did she question the benefits of Alzheimer drugs.

In the following I suggest one way of understanding this certainty, attributing it to three interrelated ways of reasoning: (i) the simple acceptance of the latest scientific information, for example the formation of the category 'BPSD' (behavioral and psychological symptoms of dementia) (see Leibing, in press); (ii) the longstanding advocacy for recognizing the 'personhood' of the patient (and therefore the 'behavioral and psychological individual' with a dementia), including calls for dementia care to address non-cognitive symptoms in a number of non-biomedical – and now also biomedical – environments (see Leibing et al., 2006), and (iii) the specific discourses of geriatrics and gerontology.

#### ALZHEIMER MEDICATIONS: FROM COGNITION TO BEHAVIOR

Although medications for cognition and those for psychiatric symptoms were clearly distinguished from one another a decade ago, more recently

one can find three major, coexisting positions regarding these two types of treatment for dementia:

1. Conservative position: medications acting on cognition are the principal treatment, and the treatment of behavioral and psychological symptoms are secondary, (e.g., Greve & O'Connor, 2005);
2. New position 1: medications originally developed to act only on cognition can be applied in a novel way, to improve activities of daily living, quality of life, and functionality (e.g., Bullock, 2005);  
New position 2: psychiatric medications, especially atypical antipsychotics, are improving activities of daily living, quality of life and functionality as core interventions in dementia care (e.g., Wancata, 2004).

Tracing the formation of the category BPSD (behavioral and psychological symptoms of dementia) demonstrates the recent merging of cognition and behavior/emotion in dementia treatment, and the shift away from viewing cognition as the central domain of dementia symptoms. One of the best-known atypical antipsychotics in the treatment of Alzheimer's disease is risperidone – produced by Janssen Pharmaceuticals, which has been actively involved in the creation and promotion of the new category BPSD. As some authors suspect, an important part of the rethinking of dementia to include non-cognitive symptoms occurred in reaction to increasingly clear statements made in the medical literature, that cognitive enhancers are not effective (enough) in treating cognitive decline (e.g., Harvard Mental Health Letter, 2004; Lenzer, 2005; NICE, 2005; Royall, 2005; Trinh et al., 2003). Janssen provided an unrestricted grant for a consensus conference organized by the International Psychogeriatric Association (IPA) in Landsdowne, VA in 1996, the event that was central to the development of the new category BPSD. 'The development of the Consensus Statement on Behavioral and Psychological Symptoms of Dementia (BPSD) represents a first step towards recognizing that *these are core symptoms of dementia* and that it is as essential to study and treat them as it is to study and treat any other aspects of dementing disorders,' wrote one of the organizers (Finkel, 1996, emphasis added). A second conference followed in 1999, resulting in more publications (IPA, 1996a, 1996b, 1996c, 2000, 2002). Afterwards updated educational materials were regularly mailed to all IPA members, in a effort which gradually changed the way health professionals understand and define dementia.

The Merck Manual of Geriatrics defined dementia the same way in 2004 as it did in 1995: 'a deterioration of intellectual function and other cognitive skills, leading to a decline in the ability to perform activities of daily living.' Nevertheless, for some researchers, the emphasis on BPSD is

changing the definition of the disease. In an IPA journal Potkin recently reversed this standard order of importance of symptom categories, defining Alzheimer's disease as '... characterized by deterioration in the *ability to perform activities of daily living* (ADL) in addition to loss of cognitive function and behavioral changes' (Potkin, 2002; emphasis added).

While the first drug to treat Alzheimer's disease, tacrine, was meant to improve memory, newer drugs are linked to the improvement of activities of daily living and psychological and behavioral problems. On Pfizer's homepage we find the following description of Aricept, a description that privileges the drug's effect on everyday activities over its effect on memory:

Several studies have revealed that these medications have a *positive impact on daily activities, behavior, and overall functioning, including memory and orientation of time and place*. Other studies have demonstrated that some of these drugs may be safe and effective over the long-term, significantly delaying the worsening of symptoms (<http://www.aricept.com/index.html>, emphasis added).

While the attention paid to non-cognitive symptoms was certainly a long-demanded, positive effect of the promotion of BPSD, the new category has had its critics. Their criticisms ran along three lines:

1. Merging symptoms as diverse as physical aggression, screaming, restlessness, agitation, wandering, culturally inappropriate behaviors, sexual disinhibition, hoarding, cursing, shadowing, anxiety, depressive mood, hallucinations and delusions (cf. IPA, 2002, p. 5) under one category is obfuscating. For example, Ballard and Cream (2005, p. 6) write that, 'the results [of studies on treating BPSD] are almost impossible to interpret, as the studies group together a range of dissimilar behavioral and psychiatric symptoms, which probably have different etiologies'.
2. Not only are symptoms merged with the use of the BPSD category, but measurements are also made of less specific entities. The shift towards trial outcomes measuring functionality, quality of life, and activities of daily living allowed positive outcomes to be calculated for clinical trials that previously had not reached statistical significance. As Katz and Marshall (2004) observed, functionality has become a new medical paradigm that has overtaken the question of normalcy. However, there is a lack of definitions and validated measurements of functionality, and their relation to drug efficacy. Also missing are critical histories of concepts such as 'quality of life' and 'activities of daily living' as new paradigms in medication studies.

3. The efficacy of BPSD-related medications is difficult to measure, since many of the associated symptoms disappear without treatment. Also, the issue of the particularly high placebo effect is not addressed in clinical trials on BPSD. As McShane and Gormley (2002, p. 241) warn, '[d]rugs are widely and often excessively used to manage BPSD. The placebo response rate is high in randomized studies. This may be because of the increased attention of triallists and the natural tendency of BPSD to resolve'.

These critiques have not gone unnoticed: as a result of them BPSD is losing its power as a category. The influential Society Alzheimer's Disease International (ADI) added a factsheet on BPSD to its website in 2004, which presented IPA data. This fact sheet has since been pulled from the website and has been replaced by one that recommends using psychiatric drugs for dementia with great care (see ADI, 2007). It seems that the British NICE study (mentioned at the bottom of the replacement fact-sheet) influenced this change in ADI's position.<sup>17</sup> However, the underlying message of BPSD – the change in biomedicine's focus on dementia – had already been communicated, and, as the interviews above show, the consequently broadened uses of medication and unspecific outcome measures ('functionality') are now part of the way doctors speak about dementia.

### **'BEHAVIORALISTS,' 'PSYCHOLOGISTS' AND THE QUEST FOR PERSONHOOD**

If the previous section of this article suggests that BPSD was, to a great extent, an invention of the pharmaceutical industry aiming to widen the applicability of medications with previously limited use, this section explains that advocates of the recognition of behavioral and psychological symptoms in fact predated the medicines (Cohen-Mansfield & Mintzer, 2005). Not all people arguing for BPSD did so to promote the bottom line of pharmaceutical companies. In fact, at the beginning of the 20th century, behavioral and psychological symptoms held a central position in the treatment of dementia. Alois Alzheimer's first descriptions of his (presenile) dementia patients (see Jürs, 1999; Maurer & Maurer, 1998), with their sometimes bizarre and sometimes sadly desperate behaviors, address many behavioral and psychological symptoms. Alzheimer treated Auguste Deters, his first famous patient, with warm baths against her agitation (balneology), as well as with outdoor physical activities, dietary measures, gymnastics, and massage against sleeping problems. Hypnosis and galvanisation (treatment of the head with light electric currencies) were also recommended. Sleeping pills were declared useful,

but to be taken with care. By the end of the last century, this view had changed cardinally: pharmacological interventions were – and remain – the predominant treatments for behavioral and psychological symptoms of dementia, despite a general consensus that non-pharmacological treatments should be tried before drugs are prescribed. Because of the prevalence of the ‘cognitive paradigm’ of dementia (Berrios, 1989, 1990) – the assumption that an impairment in cognition is sufficient to define dementia – non-cognitive symptoms (and interventions) were increasingly marginalized in biomedical discussions.

As German Berrios (1989) has argued, the claim that cognitive symptoms are the prevalent symptoms in dementia is only applicable to certain disease stages. In the earlier stages, cognitive decline is much less important than is usually assumed. The deeply-entrenched notion that dementia is reducible to cognitive problems can partly be explained by the fact that doctors, until recently, met patients only in the advanced stages of dementia, because only in the last 25 years has the hyperawareness regarding dementia in many societies permitted diagnosis in earlier stages.

BPSD addresses a real need in mental health care: the treatment of non-cognitive symptoms, which cause immense suffering and early institutionalization. Health professionals, generally non-MDs, have long been fighting for the recognition of the personhood of people with dementia notwithstanding their cognitive abilities. Book titles such as *There’s still a person in there* (Castleman, Gallagher-Thompson, & Navthons, 1999), *Hearing the Voice of People with Dementia* (Goldsmith, 1996), *The Person with Alzheimer’s Disease, Pathways to understanding the experience* (Harris, 2002), and *Speaking our Minds, Personal reflections from individuals with Alzheimer’s Disease* (Snyder, 1999) illustrate the fight against the biomedical paradigm in which the person vanishes with the diminishing of her cognitive capacities, and its resulting stigma (see also Leibing & Cohen, 2006, Section 4).

While one could call these contributions to dementia research peripheral, as they come from underfunded and often undervalued caregiver groups and helping professions, the shift of dementia research to focus on non-cognitive symptoms has resulted in the emergence of the person with dementia out of these margins. Since ‘activities of daily living’ and ‘functionality’ cannot exist or be measured without a subject, the feeling and behaving person is receiving more attention. For example, a 2004 *New York Times* article explained that ‘[o]nly recently has it become clear that emotional and behavioral troubles are nearly universal among people with Alzheimer’s disease, and the problems are frequently intractable and *more upsetting to families than the mental slowing*’ (Grady, 2004, emphasis added; see also Spalletta et al., 2004). Similarly on commercial websites – such as this one for the medication Namenda



(memantine) – the subject takes centre stage in descriptions of efficacy: ‘In fact, in this study, patients taking both Namenda and Aricept were significantly better able to handle activities of independent daily living, such as being left alone, using a telephone, and finding belongings, compared to patients in the study that were given Aricept alone,’ (<http://www.namenda.com/sections/20/proven-benefits.shtml>).

In short, the longstanding call for a person-centered approach in dementia care now has new advocates, who come with different backgrounds. This has resulted in merging of previously-separated discourses on the cognitively impaired person, the discourse of biomedicine and that of other health professionals and caregivers (see Leibing, in press).

### GERIATRICS AND GERONTOLOGY, THE ‘HOLISTIC’ SCIENCES

While the shift from cognition to a focus on quality of life, functionality and activities of daily living as indicators of efficacy was certainly facilitated by the empowerment of health professionals who have long insisted on personhood beyond cognition, there remains another important element to this history. Specifically, this has to do with the ‘holistic’ notions of patients and their suffering, often professed by doctors specializing in geriatrics – a specialty which overlaps in many areas with gerontology.

The work of zoologist Elie Metchnikoff, who coined the term ‘gerontology’ in 1908, the same year he received the Nobel Prize, reflects the tensions within geriatrics, a medical discipline predisposed to crossing over into the psychosocial domain of gerontology. As Andrew Achenbaum (1995, p. 26) has pointed out, while the scientific views of most of Metchnikoff’s peers were being transformed by Darwin’s ideas, his work remained rooted in Romantic assumptions. When Metchnikoff began working in the newly founded Pasteur Institute in Paris in 1888, he pursued his multidisciplinary approach, which his colleagues severely attacked as ‘romantic.’ The press, however, praised Metchnikoff as a ‘broad humanitarian’ – praise still valued by geriatric health professionals who often criticize exclusively biomedical approaches to treating aging people.

Besides Metchnikoff, others such as I.L. Nascher (who coined the term ‘geriatrics’ in 1909) and G. Stanley Hall maintained the hope that science, one day, could salvage people from the burdens of old age. These authors, as Achenbaum writes, initiated a debate still central to gerontology and geriatrics: ‘Was research on aging primarily the province of biomedical scientists or were its behavioral and social aspects equally important?’ (1995, p. 43)

It seems therefore only natural that gerontologists and a great many geriatricians accept that medications can now be targeted to ‘quality of life’ and related issues such as ‘functionality.’ As a consequence, and in stark

contrast to the situation only a decade ago, such practitioners are less opposed to biomedical interventions that improve a person's quality of life and do not only focus on cognition. Geriatrics, like pediatrics, is often called a holistic science. And since aging cannot be cured, geriatrics aims to promote positive aging, through: (i) slowing down biological aging processes; (ii) developing positive social relations and, (iii) overcoming negative ageing stereotypes. Currently, geriatrics is often linked to gerontology, a discipline that looks to an explicitly psychosocial paradigm in developing treatments for older people. The Brazilian society SBGG (*Sociedade Brasileira de Geriatria e Gerontologia*) unites these two sciences under one roof, as does the *International Association of Gerontology and Geriatrics* (IAGG), which now has a Brazilian president, geriatrician Dr. Renato Maia.<sup>18</sup>

This rhetoric of holism is also found in the interviews in Rio de Janeiro. For example, in the following interview excerpt, a female geriatrician weaves memory deficits and behavioral problems together almost as though she conceives them as a single entity.

I talk about Donepezil and Exelon [cognitive enhancers] to you here. So you choose between them mainly according to the profile of the patient and the profile of the caregiver, so that at the beginning of the dementia you can improve *the memory deficits*. Because there are studies saying that when you give that medication the patient becomes . . . well, the *agitation and the behavioral problems diminish*. The family does not express it exactly like that, they say: 'Look, *doutora*, he took initiative.' You don't ask if the patient has become the same than he was before, no. It is enough that in his daily activities, such as bathing, he had the initiative to grab the soap and pass it over his body, . . . he opens the car door – things he had stopped doing before, that these activities improve. We want to take the stress off of the caregiver and improve the individual's quality of life. And if he is more independent at home, I can feel satisfied, that it is what it means to improve the scales of quality of life. . . . I work with these scales, so we can quantify the effect of the medication of the patient. So for every person one needs a scale of activities of daily living until . . . well, then we pass the questions to the caregiver, right? . . . The family wants the patient to get as he was before, the family does not know, that's why we have to treat as an interdisciplinary team, not only the medication . . . (emphasis added)

### CONCLUSION: TENSE PRESCRIPTIONS?

The recent history of Alzheimer medications suggests a paradox: namely, that rationalizing the use of medication through 'uncertain' categories such as 'quality of life' and 'functionality' has created a greater certainty. This could only take place with a concurrent broadening of the concept of dementia, which occurred through the increasing 'matter of fact'

(cf. Latour, 1999), or indisputable and obvious reality, of BPSD. As a consequence, cognitive enhancers, until recently used exclusively for cognition, are now also used to enhance the quality of life of people suffering from a dementia. As part of this re-pharmaceuticalization, the biomedical rhetoric that created the demented non-person has transformed into one that enables a potentially functional individual. While it is clear that BPSD is influencing the way dementia is conceived in the scientific literature, understanding its consequences on how health professionals, patients and the general population (including decision makers) think about, treat and experience dementia requires data from fieldwork.

The data from research in Rio de Janeiro address these consequences, and the findings are striking in the extent to which the narratives of these geriatricians reflect the internalization of recent conceptual changes regarding dementia. Doctors prescribing Alzheimer medications do not feel the apparent tension between contradictory information about the drugs they prescribe, because they no longer describe the effect of these medications exclusively in terms of cognition. Rather, these practitioners focus on quality of life and related concepts, a message they also transmit to the family of the person with dementia.

At stake in Rio de Janeiro is not the issue of medications' uncertain or doubtful efficacy, the focus of international controversies. The doctors interviewed and observed for the present study expressed certainty regarding Alzheimer medication in a number of ways. One reason for this discrepancy between the global/textual and the local/practiced could be that the doctors rely on their clinical experience more than on the available body of scientific literature. Another reason for the discrepancy could be that the body of scientific literature and teaching is selective in specific ways. Brazil is a country in which pharmaceutical companies invest heavily. Although the Lula government is doing its utmost to keep prices down and to privilege generic medications (InPharm.com, <http://www.inpharm.com/view/0/home.html>), Brazil remains a lucrative country for pharmaceutical investments.<sup>19</sup> As a consequence, all of the leading Brazilian psychogeriatricians – who are also the producers of knowledge in their specialty – receive generous funding for congress organization, international travel, research, or other activities. One rarely finds an opinion critical of the pharmaceutical industry in Brazilian journals or scientific meetings. On any given day, one could find several sales representatives from pharmaceutical companies in front of the psychogeriatric unit where part of this research was undertaken.

This selective knowledge-making may have also contributed to the unquestioned absorption of quality of life issues into the discourse on medications. Nevertheless, in Brazilian psychogeriatrics, the ideal of 'holistic caring' ('the biopsychosocial paradigm'), stemming from gerontology,

emphasizes the suffering person who needs to be provided a meaningful life beyond cognition. This archetype is firmly entrenched in geriatric and gerontological discourses through long-standing education and training, and facilitates the incorporation of the relatively unspecific efficacy that accompanies recent uses of Alzheimer medications.

In this international history of dementia, the medications used to treat it, and the people it involves, doubt and certainty are tightly intertwined. Certainty is linked to the indistinction of the social and the molecular, the person and the medication. Only a multi-stranded approach is able to trace how categories important to the way we understand ourselves come to life and, eventually, drift away into life's shadow.

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### NOTES

1. It should not be forgotten that Alzheimer's disease is also a relatively recent category in North America (and other countries). See Gubrium (1986) on the beginning of public awareness in the US around 1980, or Reisberg (1981), who wrote that until recently people did not even have a name for what now is well known as 'Alzheimer's' (see Leibling, 2000).
2. See, for example, Adam Hedgecoe's (2004) discussion on the APOE-Tacrine hypothesis.
3. See the strong reactions to the British NICE guidelines that no longer recommended dementia drugs (cognitive enhancer) because of their low cost-effectiveness (e.g., Jackson, 2005). Some Alzheimer groups, working directly with families, vehemently support the continued use of these Alzheimer medications.
4. Regarding the *cognitive enhancers*, critics seem to agree that the pharmaceutical industry promotes drugs that do not significantly improve the cognitive capacities of dementia patients: '... trial reports tend to exaggerate beneficial effects and underestimate adverse effects. This is due to incomplete follow-up and the bias introduced by more early withdrawals from the active-treatment groups in a progressively deteriorating disease' (Therapeutics Initiative, 2005). This kind of statement contrasts with more positive observations such as 'The conclusion is clear: stabilizing or slowing the progression of symptoms of AD using these drugs [cognitive enhancers] is a clinically meaningful therapeutic goal' (Gauthier, 2002). Also the article by Geldmacher and colleagues (2006, p. 426), like that of many other researchers, emphasizes the benefits stemming from cognitive enhancers:

'There is substantial evidence that available treatments for AD are effective in improving or reducing deterioration in behavior, ADLs [activities of daily living], and cognition.'

5. Some side effects of traditional antipsychotics are called 'extrapyramidal symptoms' (EPS). These may involve tremors, involuntary movements, rigidity, body restlessness, muscle contractions and changes in heart rate. These symptoms are highly disturbing and can even be fatal if untreated (neuroleptic malignant syndrome). Atypical antipsychotics, which were first developed for schizophrenia, are called 'atypical' because they do not have the typical adverse effects of the first-generation antipsychotics (but see Lieberman et al., 2005). Antipsychotics in dementia treatment are used for agitation, aggression, psychotic symptoms (delusions, paranoia, etc.), and other 'challenging behavior.'
6. Regarding the *behavioral and psychological symptoms* of dementia, some articles come to the conclusion that '... the overall evidence base for the use of *psychotropic medication* remains poor' (Treloar et al., 2001, p. 445, emphasis added), and that '*pharmacological therapies* are not particularly effective for the management of neuropsychiatric symptoms of dementia' (Sink et al., 2005, p. 596, emphasis added).
7. Psychogeriatrics is a speciality that refers to mental health issues in geriatric medicine. Its main focus is the dementia. There is considerable overlap with geriatric psychiatry, old age psychiatry, psychiatry of old age, and others, to the extent that sometimes these terms are used as synonyms for psychogeriatrics (see e.g., Eastwood, 1997).
8. An article about recent trends in geriatrics in Brazil carries the subtitle 'a big country with big opportunities' (Garcez-Leme et al., 2005).
9. The general explanation is as follows: Rio de Janeiro was the capital of Brazil until 1960 when the capital moved to Brasília. Many people working for the government stayed behind in Rio de Janeiro, and they are now old. The other state with a comparable high percentage of older people is Paraíba. Here, the reason is that most young people migrate south in order to escape poverty. In Rio de Janeiro and São Paulo the 'doorman from Paraíba' is a well-known figure in urban narratives.
10. Birks finishes her article on donepezil in 2005 with the comment: 'Donepezil is associated with *some* benefits in cognition, behavior and ADL in patients with mild to moderate Alzheimer's disease after 6 months of treatment. Evidence for the effectiveness of treatment for 1 year is controversial' (Birks, 2005, p. 169, emphasis added). Before getting to this conclusion Birks also alerts that 'adverse effects were consistent' and 'were most likely to lead to withdrawal in the *first 12 weeks of treatment*' (p. 169, emphasis added).
11. In observing the doctors, subtle forms of uncertainty did sometimes come to light. The results of the observation part of the research will be explored in a subsequent publication.
12. Research and treatment of the dementias encompass several disciplines including neurology, (old age) psychiatry, and geriatrics. As opposed to what occurs in Brazil, in North America the dementias are often excluded from

mental health programs and defined as neurological. Nevertheless, when looking at the management of dementia symptoms, the treatment of these mental, emotional and behavioral symptoms is primarily psychiatric.

13. See also Pilgrim (2007) on ambiguous psychiatric diagnosis.
14. As Boholm (2003: 167) has pointed out, uncertainty can have a positive flavor as 'luck' or good 'fortune.' When it is linked to dismal or catastrophic expectations one speaks of 'risk.' For an overview about the link between risk and uncertainty see Zinn (2006).
15. Bauman (1992), though, criticized Beck for his 'optimism' in ascribing too much critical and transformative power to risk – a critique that could be extended to uncertainty (see later). Also, Bauman and Beck talk about late modern times or postmodernity in general, culturally unspecific terms. Several of the many realities existing in Brazil cannot be excluded from a certain global sensibility some authors call 'postmodern.' And, as Brazilian anthropologist Jane Russo stated (personal communication), Brazil was already postmodern before this notion came into being. This statement is related to the general notion of a Brazilian reality as contradictory and unstable (see also Leibing, 2001).
16. Jason Szabo's historical analysis of the multiple strands of doubt in medical debates surrounding the miraculous healing capacities of Lourdes in France (Szabo, 2002) is a good example of this.
17. The British National Institute for Health and Clinical Excellence (NICE), which produced guidelines about cognitive enhancers for Alzheimer's disease, suggested that the four common medications are not cost effective and should not be recommended for prescription. The argument was that the observed effects were minimal compared to the high costs. In a later paper NICE recommended further studies, because it was unclear if these cognitive enhancers were ineffective only in particular subgroups. According to Iliffe and Manthorpe (2007), the NICE guidelines will have a major impact on the public beyond British health politics. According to 'Research & Markets' (2007), a major international market research enterprise, 'the recently published NICE guidelines will only have a modest impact . . . Prescribers do not appear to guideline-prescribe.'
18. In 2005 'Geriatrics' was added to the former IAG, the International Association of Gerontology, which was founded in 1950.
19. A recent study by Lima and colleagues (2007) showed that, despite the national campaign, in the city of Belo Horizonte generic medications were almost never used by older people.

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