Understanding the meaning and doing of early stage Alzheimer’s Disease: the role of uncertainties

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Alzheimer’s Disease (AD) is a disease with a very rich cultural history, in which various scientific and popular discourses play a role (Ballenger 2006). This history has shown that AD is much more than a biomedical category. It is a complex disease that has been, and is, enacted in plenty of ways. Moser (2008) describes this in a clear way, by exploring the mattering of AD in a number of locations: an international Alzheimer’s patients’ movement; a medical textbook, laboratory science, daily care practice, parliamentary politics, general practice... etc.

Still, in medicine, the biomedical gaze at AD prevails. With medicine’s goal mainly directed to one direction, i.e. towards evidence based diagnostics and treatment, it is not surprising that the biomedical discourse on AD gets most attention. However this medical-scientific focus on the AD field, while implying an unspoken promise that it delivers certainties, leaves other views of AD marginalized. This approach ignores the fact that AD is enacted in various ways. The scientific research into AD is aiming at the possibilities of diagnosing early stages of AD. This has lead to new, ambiguous and uncertain diagnostic categories such as Mild Cognitive Impairment (MCI). Consequently, the ways in which AD is being enacted have increased even more.

In this presentation we will analyze the multiplicity of Alzheimer Diseases in different practices, on the basis of Annemarie Mol’s Body Multiple (2002). We focus especially on early stages of AD. By doing observations and interviews, we study early AD in medical practices, nursing practices, research practices and practices of patient organizations. We will show how the meaning of early AD differs from practice to practice and how this is related to the ways early AD is done. Also, we will address the question of how these different, often even conflicting, practices co-exist.

We suggest that considering how the meaning and doing of early AD reflect different types of uncertainties, helps us better understand the different practices of AD. In our analysis we will explore the role of uncertainties involved in the different ways of meaning and doing of early AD in various practices and their co-existence. We will show how in different practices, different kinds of uncertainties play a role. These uncertainties are crucial in relation to meaning of doing of AD.

We will conclude our presentation by discussing the value and limits of focusing on uncertainties in analyzing the meaning and doing of early AD.

References