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Editorial

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Dementia: Faith in Science or Faith in Pharmacy

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Returning from the 7th Global Experts Meeting on Neuropharmacology held in Milan recently and comparing this to other international conferences on dementia, neuropharmacology and neurophysiology attended in the last couple of years it's easy to feel a bit overwhelmed by the variety of drug based treatment models for Alzheimer's disease. The confidence that the various presenters have in the promise shown by their work is impressive and commendable. Yet as one of the presenters in Milan pointed out the last new Alzheimer's disease drug approved by the US Food and Drug Administration was over a decade ago. While this observation lends weight to the urgency of moving towards new pharmacological treatments for Alzheimer's disease it also suggests that it is prudent to examine the tendency towards uncritical faith in successful pharmacological intervention in dementia that dominates financial investment in dementia research and much mainstream reporting of developments in dementia care. An unexamined faith in pharmacy as a solution to all the problems of dementia constrains wider attempts to understand the experience of dementia and can inhibit the effort to explore elements of the impact of dementia from a more complex perspective.

No one would argue against the idea that faith in the scientific method has an important role in scientific endeavour. However, researchers usually distinguish between their faith in the scientific method and a religious faith. The relatively modest faith one might have in a methodical and often slowly iterative research process should be distinguished from the uncritically zealous pursuit of a fundamental panacea for a poorly understood health condition.

Alzheimer's disease is a poorly understood health condition. The relatively modest increases in research funding for Alzheimer's disease are recent and limited when considered in the context of the history and scale of research investment in other major potentially life threatening conditions, such as cancer. While Alzheimer's disease is the most frequent form of dementia worldwide, the term 'dementia' has such wide usage in the public domain that often 'dementia drug' improvements reported in the mainstream media ignore the fact that research findings may be limited only to Alzheimer's disease and not be transferable to other dementias. Replicability of studies beyond a single lab., potential poly-pharmacy interactions in real life populations, impact of side-effects on quality of life; these are just a few of the many issues brushed aside in the rush to report the latest pharmaceutical breakthrough in mainstream media. For some media reports, positive clinical results are treated as if they were as compelling as the appearance of stigmata, reassuring the faithful in their belief in the pharmacy.

Distinguishing between different forms of dementia and interrogating the implications of partial results in defining the focus and outcomes of dementia research helps not only in defining the limitations of our conclusions but differentiating our enquiries from an act of faith. Dementia is not 'the evil', some all-encompassing signifier for a host of bad things.

In a social climate that seems increasingly keen to rush to extremist judgments on a host of issues and with researchers under pressure to produce (and publish) results it is a challenge to find the space to have a conversation about the complex and multifaceted nature of dementia. A conversation that may include finding out that you were pursuing a blind alley or lead to reconsidering your conclusions because of new evidences. Not really the sort of conversation that takes place in the domain of blind faith or miracle cures.

In the *World Alzheimer Report 2016* from the Global Observatory for Health the authors call for an increasing focus on social and non-pharmacological intervention in dementia. At the 33rd International Conference of Alzheimer's Disease International in Kyoto earlier this year there were many examples in the poster presentations at the conference of the significant amount of work on from this perspective currently taking place in Japan. Many of the poster presentations were in Japanese so it may be that little of this work is known about outside of Japan. Despite the growing number of international conferences on neuropharmacology and dementia there are few international conferences primarily devoted to sharing non-pharmacological research findings. One reason for this is the lack of funding to support such conferences.

We need to have a wider perspective on dementia research than neuro-pharmacology while still retaining a commitment to methodological rigour and to recognise the value of considering more complex paradigms for framing our thinking about dementia than the pharmacological. For example, we could use climate change as a comparator framing paradigm for complex scientific change. Climate change is a well-recognised scientific phenomenon that involves not only technological innovation but large scale multi-system changes that have an impact on everyday social behaviour and political policies across energy use, transportation, infrastructure, planning and host of other areas linked by the recognition that actions across these systems have a cumulative effect on reducing climate change.

By 2050 it is estimated that 20% of the global population will be over 80. Alzheimer's Research UK estimates a dementia prevalence of 1 in 6 for those over 80 living with dementia, predominately Alzheimer's disease. No one familiar with the current state of development of pharmacological research in dementia would anticipate that by 2050 we will have an affordable and available cure for Alzheimer's disease deliverable on a global scale unimpeded by the massive infrastructure variations in national healthcare systems across the globe. We will have a massive health economic problem, however, as result of the numbers of people living with dementia in a world with a predominantly older population. By its nature dementia impacts not only on the person

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living with the illness but has wide ranging significant repercussions in their family and social network. While a pharmacological solution to dementia offers little insight into managing the global problem of increased longevity, non-pharmacological approaches often consider a wider engagement with quality of life issues for the old and very old. Even with the main forms of dementia cured there will still be an ageing population of often frail elderly people with multiple other chronic health issues significantly affecting their daily life.

Dementia research that goes beyond faith in pharmacy has an increasingly important role to play and collectively researchers need to raise their voices to insist on a much better apportioning of dementia research funding into non-pharmacological research. As with climate change, we are moving towards a future when in some sense dementia will have an impact on everyone, not least as it consumes an increasing proportion of health and care costs.

Non-pharmacological interventions that have measurable impact through quality of life improvements, reduction of symptoms and reduction of carer stress have an important role to play in dementia research and care that is frequently relegated to the margins of decisions about financial investment in research. While the construction of robust methodology and study replication for non-pharmacological interventions with patients living with dementia and their carers is a challenge, this is a challenge for the application of scientific method.

Peer review journals are part of the framework within which research scientists test out and refine their ideas. Faith in the scientific method takes on wide-ranging challenges in dementia that are unlikely to generate 'miracle cure on the horizon' headlines. A multi-system approach to dementia would include bringing much clearer methodological rigour and outcome based evaluation into important areas of the lives of people living with dementia and their careers, for example in the study of: building design, public transport, digital technology, music and art, diet, social inclusion, the value of physical interactions and the role of religious faith. Significant research funding investment is required to scale up small studies to explore the generality of effects to larger populations and to explore the requirements for transferring interventions across national cultures and local healthcare and social support infrastructures. This is the painstaking stuff of scientific enquiry with no promise of miracles.

The ability of researchers to formulate their ideas and have them tested by peers is supported by publication. This is not only about publication in prestige journals but subjecting ideas to the interrogation of critical colleagues. These arguments matter as the testing and shaping of ideas by peers takes the research scientist beyond simple faith. Without funding for something as simple as the translation of research papers into English, researchers lose the opportunity to share their work within the wider scientific community. Without the platform of publication and the opportunity to broaden network contacts those working in non-pharmacological interventions lack the opportunity to build up influence on the decisions made about dementia research funding.

We have little understanding of the extent of neuronal plasticity generally and the extent to which this may be modifiable in later life or any deterioration compensated for by environmental adjustments. In principle whether dietary changes, cognitive exercises or sensory stimulation have an impact on either the symptoms or the experience of people living with dementia is a matter better determined by evidence rather than faith. Some of the work being done with the impact of music based interventions on people living with dementia has potentially profound implications for the way we understand how the brain process and stores certain kinds of information. These non-pharmacological approach all have implications far beyond the field of dementia but currently attract a tiny proportion of the research funding compared with pharmacological studies. Their ability to generate benefit in quality of life terms for both people living with dementia and their carers across a shorter timescale with modest investment has had very limited research exploration. It is to be hoped that the Journal of Dementia as a new entrant to the field stimulates the publication of work illustrating a wide ranging of perspectives on dementia research underpinned by a rigorous approach to design and methodology that supports a multi-system understanding of dementia. It's all about faith in the science.

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