



Expectant futures and an early diagnosis of Alzheimer's disease: Knowing and its consequences



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ABSTRACT

Efforts to diagnose Alzheimer's disease (AD) at earlier stages as a means to managing the risks of an ageing population, dominate scientific research and healthcare policy in the UK. It is anticipated that early diagnosis will maximise treatment options and enable patients to 'prepare for their future' in terms of care. Drawing on qualitative data gathered across an out-patient memory service and in-patient hospital in the UK, the purpose of this paper is to examine the ways in which the hopeful promissory claims of early diagnosis as it maintains the dominant biomedical model for managing AD, are negotiated by healthcare practitioners. Developing the analytical standpoint of the sociology of expectations, this paper demonstrates that early diagnosis has the potential to 'close off' hopeful promissory visions of the future in two ways. Firstly, it (re)produces the fearful anticipations of AD built around expectations concerning the ageing future 'self', and secondly it produces uncertainty in terms of the availability of care as material resource. Whilst practitioners account for the uncertainties and anxieties it produces for patients and their families, they also convey a sense of ambivalence concerning early diagnosis. This article captures the internal conflicts and contradictions inherent to practitioners' perspectives regarding the repercussions of early diagnosis and concludes by arguing that it effaces the uncertainties and anxieties that it produces in practice as it restricts the co-existence of narratives for making sense of memory loss beyond 'loss of self', and fails to recognise care as a viable alternative for managing AD.

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1. Introduction

Efforts to improve the detection of Alzheimer's disease (AD) and increase diagnosis rates particularly at earlier stages to manage the 'impending burden' of an 'ageing population', drives current UK healthcare policy initiatives and scientific agendas (Lock, 2013: 22). According to Golomb et al. (2004), 'explosion of interest [in AD] reflects a shift in dementia research away from established disease and toward early diagnosis' (pp. 353). Scientific research is currently dominated by efforts to detect biomarkers, the earliest physical signs of the disease (see Zetterberg, 2011) and since age is the greatest risk factor for developing AD, healthcare policy initiatives have also emerged in recent years, which seek to improve diagnosis rates in the older population. Such initiatives implemented in the National Health Service (NHS) include pay-for-performance schemes such as the GP Quality Outcomes Framework (QOF) and the National Dementia Commissioning for Quality

and Innovation (CQUIN) Framework.

In the drive towards early diagnosis to manage the risks of an ageing population, the development of new techniques and technologies to identify genetic risk factors and detect biomarkers, reflects a larger transition in contemporary biomedicine which Clarke et al. (2003) describe as biomedicalisation. 'Increasingly complex, multisited, multidirectional processes of medicalization that today are being extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine' altering individuals' experiences of 'illness' in a myriad of complex ways (Clarke et al., 2010: 47). With respect to ageing, developments in biomedicine as situated within a capitalist framework more generally, also affect how we conceive the nature of 'growing old', primarily as a process amenable to the efforts in medicine to ensure a successful ageing process. 'Medical interventions are reshaping norms of ageing and standard clinical practice' (Kaufman et al., 2004: 732) with normal ageing processes recast as biomedical concerns (Estes and Binney, 1989): biomedical sciences shape the knowledge and expectations of the aged body. With respect to AD, efforts to detect the condition at earlier stages

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and control the number of individuals 'at risk' of developing the disease ensure that ways of approaching and managing the condition remain primarily within a biomedical framework (see Lock, 2013).

As a result of the political and scientific focus and government funding towards determining cause, cure and prevention of AD, care (with respect to non-biomedical intervention in healthcare practice), as an alternative for managing AD has been relatively overlooked (Lock, 2013). In the UK context, the publically funded NHS in recent years has faced (and continues to face) financial cuts with the majority of NHS trusts experiencing rising debt. Social care in the UK has also seen a marked decline in terms of funding with detrimental consequences for adequately meeting the needs of the older population(s) (see Kings Fund and Nuffield Trust, 2016). The curative model for managing AD as it sustains the hegemony of the biomedical framework both impacts individuals' experiences of ageing and memory loss and has also led to a marked decline in the funding of basic care services.

1.1. The complexities of early diagnosis

Despite the focus in research and policy on detecting AD at earlier stages, early diagnosis is a contested issue in part because the condition is nosologically contested. AD is an elusive phenomenon and the diagnosis process is a complex endeavour; symptoms associated with cognitive decline are difficult to separate from those of normal ageing processes and there remains no cure or adequate treatment options (see Gubrium, 1986; Lock, 2013). Due to the complexity of AD's aetiology, Lock (2013) is especially critical of increased efforts in biomedicine to prevent AD and establish early diagnosis. Prevention strategies in research are grounded on the conception that they will lead to an improved understanding of AD's aetiology. Yet as Lock shows, despite increased attention in research and policy on disease prevention, uncertainty around aetiology prevails.

Early diagnosis is further contested as it raises questions around for whom exactly it is better to know. The hopeful discourse around early diagnosis highlights the importance of enabling individuals to plan and prepare for their future. For example, proceeding with care arrangements and seeking advice regarding power of attorney or a living will (see Boenink et al., 2016). Yet, it is questionable as to whether this process is helpful for individuals experiencing memory problems (Boenink et al., 2016; Whitehouse, 2016) since it has the potential to produce affective consequences for patients and their families built around particular expectations of a diagnosis of AD. I refer here to the affective and emotional consequences of early diagnosis in terms of the anxieties and anticipations that it produces without confining analysis to a particular theoretical approach on affect and care. The disease remains highly stigmatised and feared and whilst the hopeful discourse around diagnosing AD in terms of enabling people to prepare for their future is promoted through popular culture and media discourse, 'contemporary public perceptions and media portrayals of Alzheimer's are almost exclusively pejorative' (Beard and Neary, 2013: 12). Moreover, as the management of Alzheimer's disease remains primarily within biomedical frameworks and given the biomedicalisation of memory loss to include earlier stages (reconfiguring the boundaries of normality) this, 'lead[s] to stigmatisation as the condition is assumed to be a death sentence' (Beard and Neary, 2013: 131). It reinforces the importance ascribed to cognition and rational thinking and the boundaries between successful and unsuccessful ageing are (re)cast as biomedical concerns (Estes and Binney, 1989; Beard and Neary, 2013). Constructions and constitutions of a diagnosis of AD, with respect to loss of self, the abject other and hopelessness for the future, suffuse patients' and practitioners'

accounts of the difficulties associated with diagnosing the condition (see Aquilina and Hughes, 2006; Beard and Neary, 2013; Taylor, 2010). Expectations of the nature of growing older and the 'senile other' further dominate accounts (Isaacs, 1972).

Overall, a diagnosis of AD sustains the privileging of biomedical intervention for managing the condition and effaces the affective, sociocultural dimensions of living with a diagnosis of AD, and experiential changes occurring in individuals (see Voris et al., 2009). The prevailing biomedical model restricts the co-existence of other narratives for making sense of AD and fails to recognise care as a viable alternative for managing the disease (Chaufan et al., 2012; Cuijpers et al., 2014; Cuijpers and Lente, 2015). Furthermore, despite research, which shows that practitioners articulate the importance of a caring model for managing AD, this approach is difficult to uphold (Apesoa-Varano et al., 2011). As physicians attempt to manage the 'symbolic power of cure' more generally with respect to dementia, care remains a 'secondary and temporary' articulation (pp. 1469). Given the limited treatment and care options and no cure for the condition, the hegemony of the biomedical model as it drives early diagnosis, further increases the uncertainties and anxieties felt by patients and their families (Lock, 2013).

It is therefore well established that early diagnosis is contested and entangled in a wider discourse of cure versus care. Yet, exactly how practitioners account for and negotiate the potential repercussions of early diagnosis with respect to both the complexity of expectations and anxieties concerning diagnosis, and the underfunding of basic care services, requires critical examination. This article examines the ways in which despite the hopeful discourse of early diagnosis, it has the potential to (re)produce patients' fears and anxieties concerning the future as the prevailing biomedical model plays out in patient-practitioner encounters. Yet, the article also captures the conflicts and contradictions concerning early diagnosis inherent to practitioners' accounts as they convey a sense of *ambivalence*: they simultaneously recognise the low expectations entangled in diagnosis and yet the 'truth' of cognitive decline is (re)produced, maintaining the dominant biomedical model for managing AD. Focussing in particular on the Science and Technology Studies (STS) literature on the sociology of 'low' expectations, this article examines the ways in which the hopeful future orientated discourse of early diagnosis is negotiated in the clinic and in doing so, highlights its affective dimensions: including hopelessness, uncertainty, anticipation and ambivalence.

1.2. Expectations and hope for the future

Early diagnosis enacts a particular hopeful vision of a future with AD built on the notion that it will enable individuals to plan and prepare for a life with AD. The body of literature particularly helpful for conceptualising such 'future orientated discourses' (Gardner et al., 2015: 1001) is the sociology of expectations. In particular work, which focuses on the *less* hopeful promissory orientations of the future; both the low and high expectations that accompany biomedical innovation projects (see Fitzgerald, 2014; Gardner et al., 2015; Pickersgill, 2011; Tutton, 2011). This 'inter-twining of low and high expectations' (Gardner et al., 2015: 1003), aligns with Moreira's (2010) work on the 'regime of truth' and 'regime of hope' for making sense of early diagnosis. Focussing on memory clinic encounters, Moreira highlights how the regime of hope (treatment) and the regime of truth (diagnosis) enable patients and their families to make sense of early diagnosis. The regime of hope drives patients and family members to seek clinical advice and is emergent in patients' and family members' expectations of treatment options. The regime of truth is emergent within the results of standardised cognitive screening tools: the 'truth' of

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