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

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Cover Page

Title: Expectant Futures and an Early Diagnosis of Alzheimer's Disease: Knowing and its consequences

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Expectant Futures and an Early Diagnosis of Alzheimer’s Disease: Knowing and its consequences

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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Keywords

UK; Alzheimer’s disease; Early diagnosis; Futures; Expectations

Highlights

Early diagnosis is privileged in healthcare policy.

Diagnosing Alzheimer’s disease is complex and entangled in fear and anxiety.

Early diagnosis (re)produces patients’ ‘low’ expectations of the disease.

The research illustrates practitioners’ anxieties concerning future healthcare.

Practitioners convey their ambivalence around practising early diagnosis.

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.

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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 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

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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.

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, Van Lente & Moors 2016). Yet, it is questionable as to whether this process is helpful for individuals experiencing memory problems (Boenink, Van Lente & Moors 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

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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, Shabahangi and Fox 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, Hollister and Fox 2012; Cuijpers, Lente, Boenink and Moors 2014; Cuijpers and Lente 2015). Furthermore, despite research, which shows that practitioners articulate the

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importance of a caring model for managing AD, this approach is difficult to uphold (Apesoa-Varano, Barker and Hinton 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.

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 ‘intertwining 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 cognitive decline which both co-exist in the space of the clinic. Extending these claims, Moreira (2010) acknowledges that whilst the clinical world is ‘dominated by the truth of cognitive decline and the hope of a cure against it’, there are moments at which patients do *not* want to find definitive solutions in terms of a cure and treatment (pp. 132). Here, the regime of care emerges as memory loss becomes collectivised. It is neither concerned with identifying the cause of cognitive change and nor does it promise the hope that interventions may alter further change. According to Moreira (2010) a ‘regime of care’ is therefore central to making sense of early diagnosis in the memory clinic beyond the confines of the clinical framework.

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In this article, I contribute to the analytical perspective of the sociology of expectations and the work of Moreira (2010) by drawing attention to the complex entanglements of hope and uncertainty in relation to the promissory claims of early diagnosis as the narrative of 'truth' and 'hope' prevails in the clinic. Developing this theoretical positioning however, this article demonstrates the emergence of *conflicting* visions of futures in practice as practitioners negotiate the consequences of the prevailing biomedical model in relation to its affective dimensions or 'low' expectations whilst simultaneously expressing their own sense of ambivalence. Practitioners account for and manage ambivalence as they negotiate the 'truth' and 'hope' or *hopelessness* entangled in early diagnosis. By problematising *later* onset AD through early diagnosis, policy makers and consequently practitioners, implicitly engage in the construction and constitution of patient expectations around a future with AD.

Methods

In this article, I draw upon data collected in two memory clinics and a hospital in a large teaching hospital trust in Yorkshire, UK. Data was collected over a one-year period and ethical approval was obtained from the relevant NHS Research Ethics Committee. Overall, this research was an ethnographic study exploring the role of cognitive screening tools in the process of diagnosing Alzheimer's disease in the clinic. These tools included the Addenbrooke's Cognitive Examination 111 and the Montreal Cognitive Assessment. In the out-patient memory clinics, I conducted observations in multi-disciplinary team (MDT) meetings with clinical professionals working across the fields of psychiatry and psychology, and observed initial assessment consultations with clinicians, patients and family members. As I was interested in the diagnosis process, I observed initial consultations where cognitive

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screening tools were used with individuals experiencing memory problems: none of these participants had been given a diagnosis of Alzheimer’s disease. Practitioners identified patients suitable for participation and I attended out-patient clinics weekly to observe initial assessments. Alongside observations, in-depth interviews were carried out with 23 healthcare practitioners working in both the memory clinics and the hospital setting, including memory nurses, occupational therapists, consultant psychiatrists, psychologists and geriatricians. Practitioners were recruited via a gatekeeper in the out-patient setting and snowball sampling was adopted to gather a range of perspectives and levels of expertise. Informed consent to carry out observations of consultations was obtained from the healthcare practitioner, patient and family member(s). A separate process of consent was adopted to carry out interviews with healthcare practitioners and to observe practitioners in MDT meetings. The fieldwork sites emerge as spaces of interactions between different kinds of practitioners with different epistemic cultures.

During interviews I focussed on the ways in which practitioners approached cognitive screening tools, their views on early diagnosis and how this may effect (and is effecting) patients and their families. Interviews were audio-recorded and transcribed verbatim. Observations of consultations exploring how the complexities of diagnosis were negotiated in practice were recorded in handwritten notes and both interview transcripts and fieldnotes were analysed thematically. I analysed data manually to manage and make sense of emergent themes without becoming overwhelmed by quantity and scope. By adopting an ethnographic approach, I investigated how AD was ‘brought into being’ within a particular set of healthcare practices; revealing the ‘situated rationality of action’ (Murphy and Dingwall 2007: 2224).

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I begin the analysis by highlighting the ways in which particular discursive representations of Alzheimer's disease emerge in the space of the clinic creating anxieties for patients and their families. The stigma attached to AD prevails which was witnessed across memory clinic encounters and confirmed across practitioners' accounts as they discussed moments where patients resisted diagnosis, fearing a future confined to institutional care. As practitioners recounted, the affective consequences of diagnosis including fear and anxiety have the potential to be (re)produced by early diagnosis. Elucidating the low expectations or *hopelessness* around early diagnosis, I develop the analysis to capture practitioners' internal conflicts concerning the benefit of early diagnosis for patients and their families. Practitioners struggle against feelings of ambivalence as they recognise that it enables patients and their families to prepare for the future and yet they are simultaneously concerned that it has the potential to cause futures filled with uncertainty and anticipation. This sense of ambivalence is complicated further as the prevailing model for managing AD has led to the underfunding of basic care resources in the UK. The article concludes by arguing that the tensions and contradictions inherent to practitioners' accounts provide an important and significant perspective for troubling the dominant biomedical model for managing AD. It is not always beneficial for patients to 'know' since dominant perceptions of the 'disease' are framed primarily around loss of self, restricting the space for other meanings of memory loss to co-exist, whilst care (non-biomedical intervention) is simultaneously undervalued and underfunded as a viable alternative for managing the disease.

Knowing and its consequences

Closing off futures - fearful anticipation

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In the following section, I highlight the ways in which practitioners accounted for fear and anxiety entangled in diagnosis more generally. I then go on to capture how the fears and anxieties concerning diagnosis are in conflict with the hopeful promissory claims of early diagnosis. As accounted for by practitioners, the 'truth' of cognitive decline has the potential to (re)produce the uncertainties and anxieties that it aims to resolve, closing off and restricting the co-existence of other meanings and experiences of memory loss.

For patients and their families, the prospect of Alzheimer's disease overall, has the potential to create huge anxiety and fear, as it remains a stigmatised condition (see Beard 2013). As Consultant Psychiatrist 1 explains,

> *'There is still an awful lot of stigma in the population generally and amongst individuals as to the nature of it [AD], a lot of fear' (Interview Consultant Psychiatrist 1).'*

Such fearful anticipation of AD given its stigmatisation and association with antiquated assumptions regarding madness and senility was witnessed during observations of consultations. Patients would often adopt the metaphor '*doolally*' to account for their symptoms and concerns following assessment, and patients would thank practitioners for not laughing or apologising for how '*stupid'* they considered themselves. Practitioners discussed and reflected on the negative discursive constructs entangled in diagnosis during team meetings, particularly in relation to the ways in which patients approached diagnostic appointments,

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> *"'A memory nurse presented the case of a patient who refused to attend an initial appointment for cognitive testing and who also refused to attend a scan appointment… a second memory nurse interrupted at this point and exclaimed that this was a regular occurrence, suggesting there is still a lot of negativity around the meaning of memory loss and its associations with dementia, which as she explained, 'a lot of patients are fearful of and reject the terms'" (Observation Notes Team Meeting Nunmill Hospital).*

In this case, the patient's refusal to attend assessment and diagnostic appointments was driven by the fearful anticipation around the meaning of diagnosis, of which there remains a great deal of negativity. As a result, the complexities entangled in the meaning of memory loss, dominated practitioners' concerns across the memory clinics. They spoke frequently about the negativity foregrounding understandings of AD, built around particular assumptions concerning future loss of 'self'.

The fear and anticipation or hopeless expectations of AD were also related to patients' conceptions of the nature of growing old and ageing 'self' (see Estes and Binney 1989). There is an intense classificatory struggle between how ageing is constructed as a success or failure, marked by decline in levels of cognitive function. Perhaps the 'truth' of cognitive decline in diagnosis produces and enacts 'fear' of stepping into the 'community of otherness' (Gilleard and Higgs 2013: 368); a state of becoming which lacks agency, choice and autonomy as Consultant Psychiatrist 1 suggests during interview,

> *'A lot of our patients will have had you know family members who historically would have had dementia when they'd have had a very potentially, very negative experience*

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> *of what it was like in the age of institutional care…so there's still a reticence I think for people to come forward.'*

At times, patients were unwilling to present with symptoms, in part because of the assumptions about dementia, which remain in existence across the population. Here, the consultant psychiatrist coded these assumptions in relation to archaic approaches towards the 'age of institutional care' (re)producing and (re)enacting the 'fear' of a 'community of otherness' (Gilleard and Higgs 2013: 368). The fear of the 'senile other' or the symbolism of senility (Isaacs 1972) (related to dementia and old age more broadly) has the potential to drive the extent to which patients 'come forward' in the clinic, since the dominant perception of AD is built around 'loss of self'. In this sense then the 'regime of hope' entangled in early diagnosis does not always drive patients to seek clinical advice (Moreira 2010). The *hopelessness* concerning the future ageing 'self' with AD had important implications for the ways in which patients engaged with diagnosis and accounted for their memory concerns. This was a point for reflection amongst all practitioners across the clinical teams; to push forward with diagnostic resolve, required acknowledgment of what testing cognition might mean for patients *in the future*.

As these extracts elucidate, the process of diagnosis and assessment had the potential to intensify feelings of uncertainty and anxiety, which as I show, was complicated further by early diagnosis. Across the memory clinics, practitioners predominantly practised 'wilful resistance' to early diagnosis and the kinds of hopeful promissory claims it enacts, they considered earlier detection to intensify feelings of anxiety about living with AD into the future. As Consultant Psychiatrist 1 asked during interview, *'are we just giving patients more years of anxiety?'* a sentiment echoed across epistemic cultures. Practitioners found

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negotiating such anticipations and anxieties difficult, requiring a great deal of emotional work in the clinic as Trainee Psychiatrist 1 explains,

> *'There's a real danger with early diagnosis…so not everybody wants a diagnosis: I had a case recently, a still on-going case that I'm seeing next week, of a gentleman in his early 70s used to be very, very high functioning, ran his own law firm and he came in; he had really bad cognitive decline. I've given them a diagnosis of dementia and him and his wife are just devastated…and yes that's good for them to know about the you know and they did want a diagnosis, but after you've given them that diagnosis in the clinic they then go home and then they sit and they think. They're you know they're literally devastated by it and you wonder you know in this case actually maybe with a kind of a couple of years of not knowing that he definitely had dementia, it might have been good for them 'cause he's very frustrated now. He's lashing out verbally at his wife 'cause he's so frustrated and worried about the future, and maybe that's not always the best thing.'*

In this case, Trainee Psychiatrist 1 reflects on the potential for early diagnosis to create further anxiety for both patients and their families. Whilst the formal classification of symptoms (the 'truth' of cognitive decline) may be helpful for individuals, it does not necessarily account for their experiences nor ease their anxieties or 'low expectations' concerning the future. Handling the information regarding diagnosis is therefore seen to require care given that the *anticipation* associated with it has important and at times adverse implications for patients and family members (Swallow 2016). Doing so requires acknowledging the implications of diagnosis within *and beyond* the space of the clinic, and for making sense of diagnosis day-to-day. In this sense a 'regime of care' (Moreira 2010)

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which challenges the sensibilities of the ‘truth’ of the ‘clinical world’ (seen here with respect to a diagnostic label) may be useful for patients and their families. The patient’s frustrations and anxieties were intensified by the very act of diagnosis itself. Perhaps as Trainee Psychiatrist 1 suggests a ‘few years not knowing’ may protect patients from the reification of unwanted anxieties about the future, which the promissory claims of early diagnosis do not necessarily account for.

What is interesting about Trainee Psychiatrist 1’s account here is that they recognise this particular patient’s desire to ‘know’ to make sense of their experiences through a diagnostic label *and* the uncertainties and anxieties instituted by this label. In doing so, they demonstrate their own internal conflict when faced with early diagnosis. At one level, there is the notion that ‘in the face of the fear of such a devastating condition [AD], and with such a possibility [early diagnosis], who could resist this hope’ (Rose 2009: 78) at the same time, practitioners contest the hopeful discourse around AD because it has the potential to ‘close off’ patient futures. Dealing with early diagnosis therefore requires practitioners to manage their own feelings of *ambivalence* as the following section will set out. Practitioners were concerned that the prevailing narrative of ‘truth’ and ‘hope’ instituted by the biomedical model (re)produced patients’ low expectations and anxieties concerning the future as it restricts the space for other narratives of memory loss to co-exist beyond ‘loss of self’.

Closing off futures: Practitioners’ sense of ambivalence

Whilst practitioners grappled with the complexity of emotions in the clinic and the uncertainties and anxieties potentially (re)produced by early diagnosis, for all members of the clinical teams a diagnosis was also upheld for enabling patients to make practical decisions

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about their future(s). As Consultant Psychiatrist 2 suggested during interview, *'early diagnosis is so important so that you can allow people to make decisions about their future themselves'*. Echoed further by Clinical Psychologist 1, *'to make sense of their experiences, to plan and change things accordingly'* whilst *'they still had capacity'* (Observation Notes MDT Nunmill Hospital). Whilst it is of course unsurprising that practitioners upheld the primacy of the diagnostic act since they are primarily trained to provide diagnosis and treatment, they also struggled against feelings of ambivalence about the *consequences* of privileging early diagnosis in the clinic. As a result, practitioners were not simply passive respondents to the privilege of the biomedical framework for managing AD (see Rose 2007). They recognised that early diagnosis is complex and should be approached with caution thereby demonstrating their own internal conflicts and contradictions concerning the benefits of early diagnosis. The following extracts from interviews with Memory Nurse 2 and Memory Nurse 3 capture this sense of ambivalence.

> *"Well that's a bit of a hornet's nest, isn't it? I suppose there's two schools of thought and I've got a foot in each circle, which is a bit, I am sitting on the fence a bit really. I think because if people want to know because they've got memory problems and it's impacting on their day to day life, yeah they need to know… they need to plan what to do, they need to be able to sort themselves …but then you see it and you think well you're gonna have to live with this diagnosis for a long, long time…I don't think everyone's aware how emotional that's gonna be for the person involved and their relatives… and I don't think that this big drive really takes [that] into account" (Interview Memory Nurse 2).*

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In *'sitting on the fence'* Memory Nurse 2 establishes their sense of ambivalence. They acknowledge that individuals may find a diagnosis helpful to make sense of their experiences of memory loss *'day-to-day'* and to make practical preparations for the future. Yet, in doing so it has the potential to efface the emotional and affective consequences of diagnosis. For Memory Nurse 2, early diagnosis has the potential to create a future filled with anxiety and uncertainty as individuals are required to live with knowing for longer. What is important here is that caring (c.f. Apesoa-Varano, Barker and Hinton 2011) is at the forefront of Memory Nurse 2's articulations as they recognise the complexity of emotions entangled in diagnosis and its repercussions. In this sense, negotiating early diagnosis requires practitioners to have *'a foot in each circle'*, mindful of both its ability to emotionally impact patients given their 'low expectations' whilst also recognising that the 'truth' of cognitive decline may be helpful for some individuals. The internal conflicts felt by practitioners were evident across the memory service. The following extract from an interview with Memory Nurse 3 further elucidates this sense of ambivalence,

> *"I've got mixed sort of feelings about it because sometimes when we go out and see our patients, a lot of our patients (this is where it kind of gets complicated) a lot of our patients don't want that assessment".*

For Memory Nurse 3, not all individuals seek a diagnostic label through formal assessment and this complicates early diagnosis. The notion of having *'mixed feelings'* also alludes to the ways in which they may struggle with their own feelings of ambivalence. Whilst early diagnosis is promoted, they recognise that not all people make sense of memory loss through formal assessment. In this sense, early diagnosis has the potential to efface the co-existence

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of other ways of dealing with symptoms and experiences of memory loss which was captured effectively during an interview with Clinical Psychologist 2,

> *'I wonder about the balance. What happens to all those people who have a diagnosis, and if there is such a value placed on them having a diagnosis, do we then lose sight of the individual at the centre of it; what it means for them to have that diagnosis, how they want that to be?' (Interview Clinical Psychologist 2).*

What Clinical Psychologist 2 describes here, is the fact that shifting diagnosis towards earlier stages may not account for the ways in which patients construct meaning around diagnosis. It has the potential to restrict ways of approaching and making sense of memory loss, effacing the 'individual' and their experiences. The values associated with diagnosis and assessment overall, may not map onto the ways in which *patients* conceive the nature of diagnosis related to their own expectations and visions of *'how they want to be'*. For Clinical Psychologist 2, privileging diagnosis creates a situation of imbalance where patients' experiences are undervalued in comparison to ways of measuring and diagnosing AD instituted by the biomedical model. The narrative of 'truth' and 'hope' prevails in the clinic (c.f. Moreira 2010). This was captured effectively during an interview with Clinical Psychologist 1,

> **'***The downside of it all is that I think that's something that people feel we can measure and value, and it's something that doctors and psychologists can get involved with and label as an activity that they're doing. Much the stuff about making the life of people with dementia worthwhile and improving their experience; it falls into the sort of much lower valued bracket of 'care', which as a society we undervalue. And so I think to a certain extent, there's sort of a little bit of a conspiracy - not a sort of*

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> *conscious one - but or a collision of motivations, that's created this. So we can set a target for it; we can measure it…it's an industry... it's much harder to describe, it's much harder to price, it's much harder to value…to do person-centered dementia care that actually improves people's lives (Interview Clinical Psychologist 1).'*

In this case, the culture of practising early diagnosis is entangled in efforts to improve and govern diagnosis rates through formal surveillance and measurement targets, which contribute to a healthcare economy. The narrative of 'truth' and 'hope' therefore prevails resulting in a 'collision of motivations' despite practitioners raising concerns about the undervaluing of care work. The lack of value associated with such work is perpetuated by the increasing demands to rationalise, legitimise and measure clinical work, which maintains the dominant biomedical model despite the ambivalence conveyed by practitioners. In this sense, for a number of practitioners, patients' experiences are undervalued in these discussions. For Clinical Psychologist 1, early diagnosis is embedded in the wider institution of the healthcare economy as 'industry', which has important implications for patients. As these extracts show, early diagnosis has the ability to constrain the affective and perhaps invisible labour, which is continually at work in the clinic. Thus far, this is seen with respect to the ways in which practitioners account for the anxieties felt by patients and their families and the undervaluing of care work.

In this section, I have examined the ways in which early diagnosis has the potential to (re)produce uncertainties and anxieties around patient futures; restricting ways of managing individuals' experiences beyond the confines of the biomedical and clinical framework. Yet, in dealing with the affective consequences of diagnosis in the clinic and patients' low expectations, a number of actors within the memory service convey a sense of ambivalence.

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Whilst they recognise that it allows patients to prepare for their future and thereby uphold the primacy of the diagnostic act, they also express their own concerns regarding early diagnosis. They account for the ways in which the prevailing narrative of ‘truth’ and ‘hope’ has led to what Clinical Psychologist 1 describes as a ‘collision of motivations’ that *maintains* the dominance of the biomedical model despite the ambivalence felt by providers. This sense of ambivalence as a further affective dimension of early diagnosis is a significant development in the ‘cure versus care debate’ for understanding how practitioners make sense of the complexities associated with early diagnosis and its repercussions. As the final section of the article will show, the underfunding of basic care resources due to the privileging of diagnosis, further complicates the tensions and contradictions inherent to practitioners’ accounts.

Closing off futures: Care as material resource and capturing the ‘bigger picture’

Across memory clinics, practitioners expressed their concerns for the increased demand on the healthcare service and underfunding of resources as Consultant Psychiatrist 3 explains,

> *‘I think referral numbers from what I understand are going up, and are likely to continue going up. As well, the resources with the economy, the resources are going down as well, particularly with social care as well. So it’s going to mean a lot more demand on the one, the service’.*

> *‘So I think it’s going to be a lot more emphasis on diagnosis, but then less support afterwards with social care budgets being reduced…so it’s a concern’.*

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Here, the prevailing narrative of 'truth' and 'hope' creates a situation of imbalance with respect to care. For Consultant Psychiatrist 3, the underfunding of social care in the UK is a direct repercussion of the privileging of early diagnosis. This was clarified further by Registrar Geriatrician 1,

> *'You have to look at the bigger picture…what kind of care are we offering these patients in terms of diagnosis and treatment…what other social care do we give to these patients? And I think that that's been in decline recently as well…and actually perhaps that's what we need to be improving, is that bigger picture of improving assessment, diagnosis, treatment and like care and support in the community.'*

Dominating practitioners' accounts across the memory clinics were concerns regarding care as Lock (2013) has also highlighted. For Registrar Geriatrician 1, care as material resource (non-biomedical intervention), is central to imagining ways of managing AD beyond Moreira's (2010) conceptualisations of the regimes of both truth (diagnosis) and hope (treatment options). Since diagnosis is privileged both within the clinic and more broadly in terms of resources, this creates particular uncertainties around patient futures, which paradoxically, it is expected to handle and sort. For Registrar Geriatrician 1, the *'bigger picture'* is crucial for making sense of memory loss beyond the diagnostic act and more broadly in terms of resources.

The consequences of a lack of social care or support post-diagnosis for the future of healthcare practice requires further critical examination. This is particularly important as healthcare commissioners may also project their uncertainty for early diagnosis and yet continue to privilege the biomedical approach for making sense of AD. As Clinical

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Psychologist 1 explains when describing the tensions which arise during local commissioning meetings,

> *'The prevailing sort of narrative is still: if we can't give them medicine then what's the point. If we can't cure it what's the point. There is still a lot - still around - certainly I've sat in commissioning meetings with GP commissioners saying, 'remind me again what's the point of early diagnosis?'*

As Clinical Psychologist 1 explains, commissioners may also project their own anticipations concerning early diagnosis. In this case however, despite articulating their concerns the narrative of 'truth' and 'hope' prevails: a cure and treatment options remain central to ways of explaining, approaching and managing AD despite the ambivalence conveyed by a number of providers. Given commissioners' concerns, the value ascribed to care as a viable alternative for managing AD, is an important avenue for further critical examination.

For Alzheimer's disease, detection at earlier stages as a means to manage the risks associated with an 'ageing population' does not necessarily mean that it 'change[s] patients' ultimate prognosis' (Aronowitz 2009: 423). As a result, early diagnosis has the potential to create uncertainties and anxieties around patient futures particularly as the biomedical model undervalues the role of care as entanglements of both material resource *and* emotional labour in the management of AD. Shifting the diagnostic act towards earlier stages instituted particular conflicting representations and expectations of the future, which had important implications for the ways in which different actors in the memory service approached early diagnosis. The significance of this analysis as it engages with the complexities of the care versus care debate, is that it demonstrates practitioners' articulations of *ambivalence*. Negotiating early diagnosis is therefore a complex endeavour as different actors recognise the

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low expectations produced by the prevailing biomedical model and yet, it remains the dominant framework for managing AD. This article has subsequently highlighted the tensions, contradictions and complexities inherent to practising early diagnosis as practitioners attempt to make sense of the prevailing biomedical model with its potential to ‘close off’ hopeful visions of the future.

Conclusion

This article brings to bear the concerns raised by practitioners with respect to early diagnosis; casting light on the anticipations and anxieties the future of an ageing population with AD produces. The prevailing narrative of ‘truth’ and ‘hope’ instituted by early diagnosis has the potential to bring forth conflicting *hopeless* visions of the future in two ways and in doing so, demonstrating the vulnerabilities of hope and optimism. Firstly, it enacts a vision of the future filled with uncertainty and anxiety since it restricts patients’ experiences of memory loss beyond conceptualisations of loss of ‘self’. Secondly, it enacts a vision of the future through which the promissory claims of early diagnosis are difficult to imagine. This is due primarily to a lack of care as material resource given the challenges facing the NHS. Overall, as the regimes of ‘truth’ and ‘hope’ prevail and the closure of the diagnostic act in the ‘clinical world’ of AD is privileged, this constrains the invisible, affective dimensions and tensions accounted for by practitioners across clinical practice.

As this article has shown, the hopeful promissory claims of early diagnosis efface the expectations, anticipations and anxieties that such work might (re)produce and perform in the

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clinic. Therefore stressing of the good associated with early diagnosis, becomes implicit in 'downplaying' the more 'tangential', invisible and *affective* consequences of promoting early diagnosis, which is uncertain and complex (Michael 2000: 30). Although this uncertainty is not necessarily a point unique to AD, practitioners attest that given the difficulty in determining a treatment or cure for AD, care as an alternative and viable option for managing the disease, is often overlooked within the prevailing (bio)medical model. Practitioners iterate that early diagnosis closes off *'care into the future'*, both in terms of the work involved in handling a diagnosis, and also in terms of resources. Despite the prevailing (bio)medical model through which AD is positioned, the consequences of the underfunding of social care in the UK as early diagnosis is privileged in research and policy, is often at the core of practitioners' concerns. Not only does early diagnosis therefore have the potential to (re)produce the anxieties and anticipations about the future with AD for patients, it also creates anxieties for practitioners.

Yet, this article has not only dealt with the repercussions of the prevailing biomedical model for managing AD entangled within a wider discussion of the cure versus care debate, it has also captured the tensions and contradictions inherent to practising early diagnosis. Whilst a number of practitioners attest that diagnosis may enable patients to 'prepare for their future' they simultaneously recognise that a diagnosis has affective and emotional consequences which may be difficult to negotiate. Dealing with early diagnosis therefore requires practitioners to manage their own feelings of *ambivalence*. Practitioners themselves struggle to deal with the benefits of early diagnosis given its ambiguity; it has the potential to create a future filled with uncertainty and anxiety as it restricts the co-existence of other meanings of memory loss beyond 'loss of self', and reinforces the construction that 'cognition is the decisive carrier of personhood' (Leibing 2006: 258). In capturing the ways in which practitioners experience the ambiguity around early diagnosis and in turn convey their sense

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of ambivalence, this article draws together the consequences of the cure versus care debate in relation to its affective dimensions or ‘low’ expectations. This is significant in that it addresses the gap in the literature which pertains to the ways in which practitioners negotiate the complexities of emotions or low expectations in the clinic regarding a future with AD, whilst simultaneously expressing their own feelings of ambivalence.

Yet, despite practitioners accounting for the low expectations enacted by early diagnosis and in doing so dealing with their own sense of ambivalence, the dominance of the biomedical model with respect to diagnosis is maintained and (re)produced. To negotiate this the trainee psychiatrist suggested that it may be useful to protect patients by giving them a ‘few years not knowing’, yet in practice, practitioners are constrained by the drive in healthcare policy to diagnose AD at earlier stages through pay-for-performance schemes such as those outlined in the introduction. Further research could examine the impact of these initiatives on the affective dimensions of early diagnosis and the ways in which the biomedical model is continually upheld and privileged despite practitioners constructing (temporary) articulations of care (Apesoa-Varona, Barker and Hinton 2011).

The sense of ambivalence conveyed by practitioners as they negotiate the narrative of ‘truth’ and ‘hope’ as described by Moreira (2010) is previously unaccounted for in literature, which critically engages with the complexities of the cure versus care debate. Such ambivalence also creates a space in which stakeholders may need to contemplate and debate the privileging of early diagnosis: practitioners are not simply passive respondents to the processes of (bio)medicalisation which circulate across practitioner-patient encounters. In this sense, further research is also required to account for patients’ and family members’ experiences and articulations of early diagnosis particularly with respect to the challenges

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facing the NHS and the underfunding of social care in the UK. Overall, this article hopes to offer a brief insight into early diagnosis as it shifts the overlooked expectations of patients and concerns of practitioners; producing anxieties and uncertainties that it is expected to resolve. In privileging the biomedical model for framing and making sense of AD, policymakers should pay due attention to the affective labour at work, and the complexities of a healthcare system through which diagnosis is privileged and care underfunded. In doing so, encouraging an everyday sensibility to managing the ambiguities of AD than the privileging of early diagnosis allows in the space of the clinic.

References

Apesoa-Varano, Esther C., Judith C. Barker and Ladson Hinton. 2011. “Curing and caring: the work of primary care physicians with dementia patients.” *Qualitative Health Research,* 21 (11): 1469-83. doi: 10.1177/1049732311412788

Aquilina, Carmelo and Hughes, Julian C. 2006. “The return of the living dead: agency lost and found?” In *Dementia: Mind, Meaning and the Person*, edited by Julian C. Hughes, Stephen J. Louw, and Steven R. Sabat, 143-61. Oxford: Oxford University Press.

Aronowitz, Robert A. 2009. “The converged experience of risk and disease”. *Milbank Quarterly*, 87 (2): 417-442. doi:10.1111/j.1468-0009.2009.00563.

Beard, Renée L, and Tara M. Neary. 2013. “Making sense of nonsense: experiences of mild cognitive impairment.” *Sociology of Health & Illness*, 35 (1): 130-146. doi:10.1111/j.1467-9566.2012.01481.

ACCEPTED MANUSCRIPT

Boenink, Marianne, Harro Van Lente, and Ellen Moors. 2016. *Emerging Technologies for Diagnosing Alzheimer's Disease: Innovating with care.* London: Palgrave Macmillan.

Chaufan, Claudia, Brooke Hollister, Jennifer Nazareno, and Patrick Fox. 2012. "Medical ideology as a double-edged sword: The politics of cure and care in the making of Alzheimer's disease." *Social Science & Medicine*, 74 (5): 788-795. doi: 10.1016/j.socscimed.2011.10.033

Clarke, Adele. E., Janet K. Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman. 2003. "Biomedicalization: Technoscientific transformations of health, illness, and US biomedicine." *American sociological review*, 68 (2): 161-194. doi:jstor.org/stable/1519765

Cuijpers, Yvonne, and Harro Van Lente. 2015. "Early diagnostics and Alzheimer's disease: beyond 'cure' and 'care'." *Technological Forecasting and Social Change*, 93: 54-67. doi: 10.1016/j.techfore.2014.03.006

Cuijpers, Yvonne M, Harro Van Lente, Marianne Boenink, and Ellen H. M. Moors. 2014. "Quandaries of Responsible Innovation: The Case of Alzheimer's Disease." In *Responsible Innovation 1: Innovative Solutions for Global Issues*, edited by Jeroen van den Hoven, Neelke Doorn, Tsjalling Swierstra, Bert-Jaap Koops, and Henny Romijn, 239-254. Netherlands: Springer.

Estes, Carroll L, Elizabeth A. Binney. 1989. "The Biomedicalization of Aging: Dangers and Dilemmas." *The Gerontologist*, 29 (5): 587-596. doi: org/10.1093/geront/29.5.587

ACCEPTED MANUSCRIPT

Fitzgerald, Des. 2014. “The trouble with brain imaging: Hope, uncertainty and ambivalence in the neuroscience of autism.” *BioSocieties*, 9 (3): 241-261. doi:10.1057/biosoc.2014.15

Gardner, John, Gabrielle Samuel, and Clare Williams. 2015. “Sociology of Low Expectations Recalibration as Innovation Work in Biomedicine.” *Science, technology & human values*, 40 (6): 998-1021. doi: 10.1177/0162243915585579

Gilleard, Chris, and Paul Higgs. 2013. “The fourth age and the concept of a ‘social imaginary’: A theoretical excursus.” *Journal of Aging Studies*, 27 (4): 368-376. doi: 10.1016/j.jaging.2013.08.004

Golomb, James, Alan Kluger, and Steven H. Ferris. 2004. “Mild cognitive impairment: historical development and summary of research.” *Dialogues in clinical neuroscience*, 6 (4): 351-367.

Gubrium, Jaber. F. 1986. *Oldtimer’s and Alzheimer’s: the descriptive organisation of senility*, Greenwich: JAI Press.

Isaacs, Bernard. 1972. *Survival of the unfittest: A study of geriatric patients in Glasgow*, London: Routledge and Kegan Paul.

Kings Fund and Nuffield Trust. 2016. “Social Care for Older People: Home truths.” http://www.kingsfund.org.uk/publications/social-care-older-people.html. Accessed September 2016

ACCEPTED MANUSCRIPT

Leibing, Annette. 2006. "Divided Gazes: Alzheimer's disease, the Person within, and Death in Life." In *Thinking about Dementia: Culture, Loss, and The Anthropology of Senility*, edited by Annette Leibing and Lawrence Cohen, 240-268. New Brunswick, NJ: Rutgers University Press.

Lock, Margaret. 2013. *The Alzheimer conundrum: Entanglements of dementia and aging*, Princeton, NJ: Princeton University Press.

Michael, Mike. 2000. "Futures of the present: from performativity to prehension." In *Contested futures: a sociology of prospective techno-science*, edited by Nik Brown, Brian Rappert, and Andrew Webster, 21-42. Aldershot, UK: Ashgate.

Moreira, Tiago. 2010. "Now or later? individual disease and care collectives in the memory clinic." In *Care in Practice: On Tinkering in Clinics, Homes and Farms*, edited by Annemarie Mol, Ingunn Moser, and Jeannette Pols, 119-141. transcript Verlag: Bielefeld

Murphy, Elizabeth and Robert Dingwall. 2007. "Informed consent, anticipatory regulation and ethnographic practice." *Social Science & Medicine,* 65 (11)**,** 2223- 2234. doi: 10.1016/j.socscimed.2007.08.008

Pickersgill, Martyn. 2011. "'Promising' therapies: neuroscience, clinical practice, and the treatment of psychopathy." *Sociology of Health & Illness,* 33 (3): 448-464. doi:10.1111/j.1467-9566.2010.01286

ACCEPTED MANUSCRIPT

Rose, Nikolas. 2007. “Beyond medicalisation.” *The Lancet*, 369 (9562): 700-702. doi:10.1016/S0140-6736(07)60319-5

Rose, Nikolas. 2009. “Normality and pathology in a biomedical age.” *The sociological review*, 57 (2): 66-83. doi:10.1111/j.1467-954X.2010.01886

Swallow, Julia. 2016. “Understanding Cognitive Screening Tools: Navigating uncertainty in everyday practice.” In *Emerging Technologies for Diagnosing Alzheimer’s Disease*, edited by Marianne Boenink, Harro Van Lente and Ellen Moors, 123-141. London: Palgrave Macmillan

Taylor, Janelle. 2010. “On recognition, caring and dementia.” In *Care in Practice: On Tinkering in Clinics, Homes and Farms*, edited by Annemarie Mol, Ingunn Moser, and Jeannette Pols, 119-141. transcript Verlag: Bielefeld

Tutton, Richard. 2011. “Promising pessimism: Reading the futures to be avoided in biotech.” *Social Studies of Science*, 41 (3): 411-429. doi: 10.1177/0306312710397398

Voris, Ed, Nader Shabahangi and Patrick Fox. 2009. *Conversations with Ed: Waiting for Forgetfulness: Why Are We So Afraid of Alzheimer's Disease?* Oakland, CA: Elders Academy Press.

Whitehouse, Peter. 2016. “The Diagnosis and Treatment of Alzheimer’s: Are we being (ir)responsible?” In *Emerging Technologies for Diagnosing Alzheimer’s Disease: Innovating with care*, edited by Marianne Boenink, Harro Van Lente and Ellen Moors, 123-141. London: Palgrave Macmillan.

ACCEPTED MANUSCRIPT

Zetterberg, Henrik. 2011. “New diagnostic criteria for Alzheimer's disease.” *Biomarkers in Medicine*, 5: 407-409.

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