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Constructing classification boundaries in the memory clinic: negotiating risk and uncertainty in constituting mild cognitive impairment

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Abstract Determining the boundaries around processes of 'normal' ageing and pathological cognitive deterioration associated with Alzheimer's disease (AD) is a difficult process, complicated further by the expansion of the disease category to include mild cognitive impairment (MCI). MCI is a label used to identify individuals with the symptoms of cognitive deterioration not attributable to 'normal ageing' but deemed to be 'at risk' of developing AD despite clinical uncertainty around whether individuals will go on to develop the condition in the future. Drawing on qualitative data gathered across an out-patient memory service, this article examines practitioners' accounts of the complexity associated with constructing the boundaries around MCI, AD and age in the clinic. Practitioners utilise uncertainty by classifying patients with MCI to keep them on for review to account for the possibility that patients may go on to develop AD but they also recognise the difficulty in predicting future progression to AD. Negotiating classification boundaries in the clinic is, however, not only about managing uncertainty regarding potential future risk but also about navigating the wider social and political context in which ageing and cognitive deterioration intersect, and are constructed and managed.

Keywords: Alzheimer's disease, mild cognitive impairment, ageing, diagnostic classification, uncertainty

Introduction

In an effort to meet the needs of an 'ageing population' and anticipated increase in the number of individuals developing conditions associated with age such as Alzheimer's disease (AD), there has been an intensified search for a cure and research investment to prevent or detect the condition at earlier stages (Lock 2013a, 2013b). The risk of developing cognitive deterioration associated with AD has become a 'problem' to be medically managed. Classifying AD is complex; however, it is ambiguous and nosologically contested and it is difficult to establish and separate the processes of 'normal' age-related cognitive decline from pathological deterioration in the clinic (Gaines and Whitehouse 2006, Hardy 2006). Instruments for screening cognitive function such as the Addenbrooke's Cognitive Examination 111 and the Montreal Cognitive Assessment are used in clinical practice in the UK to detect the initial stages of cognitive decline, alongside diagnostic technologies such as magnetic resonance imaging (MRI) scans, computerised tomography (CT) scans, and blood tests. These tests are primarily used to rule out the possibility of other conditions (Bender 2003). Physical or mental health concerns can also complicate the classification process, and 'messy' patient narratives and results from cognitive screening tests do not necessarily fit neatly into a pre-defined AD category (Manning 2000). If a categorisation of AD is contested, the question remains as to how practitioners negotiate the *boundaries* of the condition in the clinic, particularly as they are continually being reconstructed.

Expansion of AD: problematising age-related cognitive decline and emergence of mild cognitive impairment

As Moser (2016) argues, AD has become a 'matter of concern', demonstrated by healthcare policy initiatives aimed at increasing diagnosis rates, the influx of research funding to determine cause of the condition, alongside the rise in 'dementia services' and 'memory clinics', all of which position dementia as a priority health concern. In response to difficulties establishing cause, cure and effective therapeutic interventions for AD, there has been a move towards expanding the disease category to include pre-symptomatic or earlier stages of AD. The move towards a 'pre-symptomatic disease model' of AD, partly in response to clinical trial failures, firmly cements the management of the condition within a biomedical framework (see Lock 2013a, 2013b). As Lock (2013b) argues, the widespread assumption concerning the 'rapidly spreading epidemic' of AD marked by increasing ageing populations and the lack of treatment for the condition have resulted in efforts to prevent the condition or detect at earlier stages. The nature of growing old, of which cognitive deterioration may be a significant factor, has become (re)enacted as a 'problem' to be medically managed with consequences for how ageing as a process is constructed as success or failure (see Estes and Binney 1989, Kaufman *et al.* 2004): 'cognitive health has joined physical health as a key indicator of successful ageing' (Peters and Katz 2015: 285).

Coupled with the emergence of this pre-symptomatic disease model, the Dubois *et al.* (2007) criteria and National Institute of Ageing-Alzheimer's Association diagnostic criteria in 2011 included mild cognitive impairment (MCI) as a formal category to account for symptoms of cognitive decline associated with the earliest stages of pathological deterioration, and to label those 'at risk' of developing AD in the future (see Lock 2013b, Leibing 2014). MCI was initially utilised to facilitate research and has since been adopted clinically to initiate 'watchful waiting' of individuals presenting with cognitive difficulties (see Beard 2016, Peterson *et al.* 2014). Clinically, MCI is defined as 'the "symptomatic pre-AD stage" on the continuum of cognitive decline, characterised by objective impairment in cognition that is not severe enough to require help with usual activities of daily living' (Langa and Levine 2014: 2551). Beard and Neary (2013) describe the incorporation of MCI into the new diagnostic guidelines as the 'diagnostic creep of Alzheimer's', reflecting increasing efforts both clinically and scientifically to categorise the earliest stages of cognitive decline, and manage the risks of an increasing ageing population (p. 12). In the US, however, the fifth addition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM–IV) has replaced 'dementia, delirium, amnestic and other cognitive disorders' with a new categorisation, 'neurocognitive disorder', while also distinguishing between 'major' and 'mild' disorders (see Sachs-Ericsson and Blazer 2014). Mild neurocognitive disorder is the revised categorisation of MCI and is defined by the presence of deterioration which may *or may not* progress the development of major neurocognitive disorders such as dementia. It is legitimated as a discrete category within this version of the DSM and is explicitly *not* framed solely as the symptomatic pre-AD stage. MCI, however, dominates clinical practice as a means to manage the risks of an ageing population and therefore risks of developing age-related conditions such as AD (see Beard and Neary 2013).

There is a substantial degree of uncertainty therefore around the meaning of MCI to describe and/or explain the earliest stages of cognitive decline associated with AD (see Peters and Katz 2015). As Gaines and Whitehouse (2006) argue, categories such as MCI 'reveal increasing ambiguity rather than clarity' (p. 62) serving primarily to support the work of practitioners and scientific researchers (see also Moreira *et al.* 2009). How the label is used in clinical practice is also a point of contention among practitioners: there are those who claim that it is clinically useful to describe cognitive deterioration *not* thought to be associated with the earliest symptoms of AD, and those who utilise it to describe individuals 'at risk' of developing AD (see Beard and Neary 2013). MCI as a label should be approached with care and caution particularly as it raises questions concerning the ageing brain, with the potential to lead to the pathologisation of 'normal forgetfulness' (Peters and Katz 2015). It is also difficult to determine which patients labelled with MCI will go on to develop AD in the future (Peterson *et al.* 2014).

The expected increase in prevalence of AD coupled with the efforts to detect the condition at earlier stages also presents a set of unique challenges for healthcare practitioners, patients and families, ranging from increased pressure on memory services with regard to referral rates, to the provision of health and social care post-diagnosis in a period of austerity in the UK. Public funding for social care has fallen dramatically given widespread austerity measures introduced by the previous coalition and current Conservative government (Stoye 2018). This underfunding and availability of care post-diagnosis is a concern for memory service practitioners and has specifically impacted the practising of early diagnosis in memory clinics (see Swallow 2017). The move towards early diagnosis more generally, effaces care as a viable alternative to managing the condition: 'care becomes equated with passive acceptance rather than active intervention' (Moser 2016: 181).

Drawing on qualitative data gathered across an out-patient memory service in the UK, this article examines practitioners' accounts of the uncertainty around determining classification boundaries and constructing MCI. Negotiating uncertainty in the clinic depends on two sets of interrelated practices. Firstly, it depends on the 'language of risk' (Webster 2002: 447) with respect to practitioners' efforts to manage and identify symptoms associated with developing AD in the future and secondly on negotiating the social and political context in which ageing, cognitive deterioration and AD are constructed, and cognition reified as a 'problem' to be medically managed through wider efforts to promote early diagnosis and detection.

Diagnosis and the role of risk and uncertainty in health care

Constituting the diagnostic boundaries of disease in the clinic is an interpretive and relational process; diagnosis sorts the 'real from the imagined' (Jutel 2009: 279) and yet is also a space for contestation and negotiation, with powerful effects and consequences for patients, practitioners and the organisation of healthcare practice (Bowker and Star 2000, Jutel 2009, 2015, Jutel and Nettleton 2011, Rosenberg 2002, 2003, 2006). Entangled in the construction or making of diagnostic categories are the negotiations which lead to the construction of the boundaries of disease, complicated by (bio)medicine's authority in categorising pathology at earlier stages. The shifting or blurring of the boundaries of disease leads to the emergence of new disease entities (see Brown 1995, Clarke *et al.* 2003, Conrad 1992, 2005). Previous work in the sociology of diagnosis has explored these 'grey' areas of diagnosis, for example with respect to analysing the process of labelling pre-disease risk states in cancer (Aronowitz 2009, Gillespie 2012), and the sense of liminality (see Timmermans and Buchbinder 2010) this provokes for practitioners and patients as well as analysing how the uncertainty around contested conditions such as depression or attention deficit hyperactivity disorder is managed in practice (see Kokanovic *et al.* 2013, Rafalovich 2005). Timmermans and Buchbinder (2010) examine the social significance of the expansion of newborn screening in the US, arguing that patients are placed in a state between normal health and pathology, which leads to ambiguity and uncertainty. They argue that this liminal space is '"uncomfortable" for patients and practitioners, who will exert pressure to fold an incomplete characterization back into more conventional categories' (p. 410). The 'functionality' of diagnosis (Jutel 2015, Timmermans and Buchbinder 2010) is therefore called into question as the boundaries of classification shift to include intermediate states. Alongside debates concerning efforts to define and categorise risk as producing new forms of uncertainty in health care, there has also been a renewed focus more generally in the sociology of diagnosis on the role of uncertainty in diagnostic practice (see Latimer 2013). As Latimer (2013) and Reed *et al.* (2016) have argued, rather than privileging efforts to eliminate forms of uncertainty in health care they demonstrate how uncertainty can be productive and enabling, serving to return the act of decision-making to the clinic.

As Jutel (2015) contends, a discrete diagnostic category must be positioned within its wider social context where analysis of a particular disease and diagnosis should 'provide[s] insight into the broader social and structural constraints of the society' (p. 844). With respect to categorising those at risk of AD through labels such as MCI, the ageing process (age is the greatest risk factor for developing AD) is increasingly seen as a 'problem' to be medically managed where 'successful' ageing encapsulates the notion that we are autonomous individuals responsible for how we grow old, and therefore the extent to which we are 'at risk' of developing diseases associated with age such as AD. There is an intense classificatory struggle between how ageing is socioculturally constructed as a success or failure, marked by decline in cognitive function with the potential to reconfigure normality (Gilleard and Higgs 2013, Grenier *et al.* 2017). Moreover, cognitive deterioration associated with conditions such as AD is entangled with wider cultural narratives of 'loss of self' where fear of developing the condition and its stigmatisation persists (see Beard and Neary 2013, Latimer 2018, Swallow and Hillman 2018). 'Powerful assumptions' (Gilleard and Higgs 2013: 369) about ageing and also AD reside in the population and infiltrate the practices of the clinic.

In this article I develop work within the sociology of diagnosis in emphasising the role of uncertainty in health care by exploring how practitioners negotiated the uncertainties around classification boundaries, focusing in particular on the construction of MCI as an intermediate disease category. Rather than disposing of patients who, for example, have a borderline score on a cognitive screening test, uncertainty creates a space where patients are kept on for review (Latimer 2013): there is the possibility that patients may go on to develop the condition in time and for which the label MCI is therefore useful. However, when faced with 'risk', the utilisation of uncertainty through the label MCI was not approached unequivocally as practitioners acknowledged the difficulty in predicting future progression to AD, the lack of available treatment options and availability of care resources post-diagnosis. The 'functionality' of diagnosis is called into question with some practitioners actively not wanting to 'fold in' to a diagnostic category (see Timmermans and Buchbinder 2010). The contestation around MCI as a discrete category extends beyond uncertainty concerning the future and the potential ambiguity it provokes for both practitioners and patients, it is also constitutive of the wider social, economic and political context in which AD classification boundaries are constructed.

Methods

Data for the article were drawn from a qualitative study of a memory service and secondary healthcare site in Yorkshire as part of an ESRC-funded doctoral study titled ‘The Role of Instruments for Screening Cognitive Function and Alzheimer’s disease: A Sociological Exploration’ [grant number: ES/J500215/1]. This qualitative study included observations in multidisciplinary team meetings (MDT), observations in initial consultations with patients and professionals where cognitive screening tools were used, and interviews with practitioners working in psychiatry, psychology and gerontology. The study was approved and granted NHS Research Ethics Committee approval. The overall aim of the study was to examine how healthcare practitioners negotiate the complexity entangled in diagnosing AD through the use of cognitive screening tools. Opening up and interfering with current diagnostic practice to examine AD ‘in the making’ was useful for reflecting on how healthcare practice was dealing with, and responding to, the increased number of referrals to specialist memory services in what is described as an ‘ageing population’ in the UK. Despite the emergence of memory clinics and services as a means to increase diagnosis rates, many individuals experiencing problems with cognition, and who will go on to be diagnosed with AD, will not pass through this system: diverse and fragmented diagnostic practices remain.

Sample

The majority of the fieldwork was conducted in two teams in the memory service. I observed team meetings, hospital wards, offices and consultation rooms. Observations of team meetings and clinical encounters were focused and selective, and I provided ‘thick descriptions’ (Geertz 1973) of these encounters to reveal the ‘situated rationality of action’ (Murphy and Dingwall 2007: 2224). I supplemented the in-depth data from these observations with interviews with healthcare practitioners.

Data for this article were drawn from in-depth interviews with 23 healthcare practitioners working in the memory clinics. Initially, practitioners were recruited via a gatekeeper and I employed snowball sampling to gather a range of expertise and perspectives. Informed consent was obtained from all patients, family members and practitioners present in the out-patient appointments and hospital setting. Separate consent was obtained from practitioners to observe MDT meetings and carry out interviews.

I carried a notepad and made fieldnotes during observations. The fieldnotes contained exhaustive information of encounters – briefing with the practitioners prior to consultation, the consultation itself, de-brief following the consultation and the team meetings. They described interactions, relations, verbal practices, non-verbal practices and personal reflections. Consultations and team meetings were not audio-recorded and I transcribed the written notes following fieldwork. Interviews were semi-structured, audio-recorded and ranged from 30 minutes to 1 hour 30 minutes in length. Interview schedules were approached as guides, allowing for in-depth development of key points and to reflect on questions and refine where necessary. Interview audio files were transcribed *verbatim*. With respect to data analysis, I adopted an inductive, reflexive approach and developed themes, categories and interpretations to illuminate the areas of inquiry of pertinence to the research.

Across the following analysis, I draw on practitioners’ accounts to capture the ways in which the boundaries of AD were negotiated in practice, focussing specifically on the emergence and utility of MCI. In the first section of analysis, I draw on practitioners’ accounts to capture the ways in which they described mobilising uncertainty (classifying cognitive deterioration not yet perceived to be AD) through deferral work (see Latimer 2013): keeping patients on in the service for monitoring and to account for the possibility that patients may go on to develop AD. The practice of keeping patients on in the service was an interesting finding given the increasing demand placed on memory services in the UK generally. Rather than disposing of patients with cognitive deterioration (c.f. Berg 1992), practitioners mobilised this uncertainty, which extended out to utilising the label MCI. I then develop the analysis to capture how expectations around ageing and its relationship with cognitive deterioration impacted how practitioners constructed the boundaries of classification and utilised the label MCI beyond efforts to account for 'risk'. The 'functionality' of MCI (see Timmermans and Buchbinder 2010) was questioned by practitioners. Classifying patients with MCI was a process driven by the expectations around ageing as related to cognitive function as well as the negative discursive constructs around AD, which shaped practitioners' ambivalence in approaching the boundaries of classification.

Utilising uncertainty: keeping patients in the memory service

Across the memory clinics, patients were referred predominantly by their General Practitioner (GP) to the psychiatric memory service for in-depth testing, which included cognitive screening tests, MRI scans, CT scans and blood tests. Identifying AD in the clinic was complicated if patients scored particularly well or particularly poorly on a cognitive screening test. This was described by practitioners as a 'borderline score' as Consultant Psychiatrist One explains:

> I suppose if you've got, so patients who've got, where their working diagnosis is uncertain, if they score unexpectedly well or poorly on a test which doesn't mirror the history, what would potentially be a reason for sort of referring on for neuropsychological testing.

Rather than disposing of uncertainty concerning a borderline score, the clinic emerged as a 'space that actually thrives on the imprecise' as borderline cases were passed over to different clinical teams such as neuropsychology for further and more in-depth testing (Latimer 2013: 103). Uncertainty concerning a borderline score was therefore utilised by practitioners as a way to keep patients on in the service as the following extract from an interview with Memory Nurse One highlights:

> Looking at the cognitive test I think the cut off for the ACE 111 (I'd have to look it up to know exactly) but I think it's kind of mid 70s so if somebody's scoring over the mid-70s out of 100 on the test, you'd be thinking is this a known AD or is this just a normal ageing process? Sometimes only time will tell on that, sometimes you just have to go back in 12 months and see if there has been any deterioration really.

As Memory Nurse One explained, a patient scoring 70 or above on the ACE 111 did not constitute a classification of AD nor did it constitute processes of normal ageing. In recognition of this, Memory Nurse One stressed the importance of keeping patients on and extending potential classification to a point in the future, 'sometimes you just have to go back in 12 months and see if there has been any deterioration' – there is a possibility that patients may travel beyond the borderline towards diagnostic closure. This finding is important as it demonstrates that despite the increased pressure on memory service clinics, for some practitioners it was important to keep patients on for 'watchful waiting' (Peterson *et al.* 2014).

Practitioners also discussed how a borderline score drove their utilisation of the label MCI as the following extract from an interview with Memory Nurse Two[1] demonstrates:

> Well I suppose when we use these tests, if somebody's functioning wise is not too impaired, hasn't changed that much and they get a borderline score, then you would say it's probably

> a mild cognitive impairment. If they score quite low but they're still functioning, and there's no vascular things nothing to show on the brain scan, it'd be mild cognitive impairment but at that stage we would continue to monitor because people do tend to go on to develop AD and have problems trying to access things and support themselves so we would try and kind of advocate for people like that.

Here a borderline score was used to navigate categorisation of MCI. The borderline score became and was transformed as useful (Latimer 2013) which led to a formal categorisation of MCI. However, as Memory Nurse Two clarified, this was far from a simple process, related to how different practitioners within the service interpreted the test results.

Across the memory service, the term MCI was predominantly used to describe a distinct set of symptoms as Clinical Psychologist Three explained, MCI is 'a description of a presentation or certain symptoms that people present that aren't quite in that kind of clinical diagnostic criteria of being able to call it AD'. Rather than disposing of these symptoms with respect to discharging patients from the memory service, MCI emerged as a vehicle for the management of ambiguity in the clinic, which was both resisted and accepted by practitioners. As I will show further in the article, this tension was entwined with broader concerns around the lack of treatment and availability of social care post-diagnosis, calling into question the overall functionality of an MCI diagnosis.

The following extract from an interview with Memory Nurse Six captures the way in which MCI was at times used as a means to direct patients into services:

> Something like 50 per cent of people who get diagnosed with MCI go on to develop AD so to have that on record shows that we need to do some watchful waiting somewhere down the road so it's useful to have someone on the pathway to introduce the idea this might get worse but at the moment we're just going to do some watchful waiting but it gets people into services; it gets both the GP and us ready and aware that things might change.

This was echoed by Memory Nurse Five during interview, who explained:

> I think it's worthwhile having that diagnosis [MCI] as I say, certainly for some people and younger people because it can go on to become AD and us in the memory service can, we can keep an eye on that and we can re-visit in 6 months or whatever, a year and just revaluate so they're on the radar kind of thing for possible progression so it had value in that sense.

Here, despite the ambiguity around whether symptoms of MCI will progress to AD, the memory nurses both clarified that this is sufficient to warrant 'watchful waiting' which enables them to 'keep an eye on' their patients. MCI enabled practitioners to monitor patients in the service and was described by practitioners as useful for making sense of the uncertainty around cognitive decline which was not yet attributable to AD.

Yet, it was also this uncertainty regarding future progression and the notion of being 'at risk' which was simultaneously resisted by practitioners. Often practitioners were reluctant to label individuals with MCI as Memory Nurse Two explained when asked during interview to discuss the value they ascribed to the term:

> Well personally no. I just kind of think you're – either you've got AD or you haven't, you've either got memory problems that are ageing or not, and at the moment if it's not AD (it's an ageing process) 'cause it might not turn into AD we know they normally do [progress] so no personally I don't think it's that meaningful. People can come back and

> see us whenever they want but they don't need to be told they've got MCI but that's my personal view and I could be completely wrong.

While MCI ensures that patients are kept within the service, practitioners also demonstrated their ambivalence towards the label as a discrete category as demonstrated by Memory Nurse Two. As they explained, the label may be unproductive for patients because of the uncertainty regarding disease progression and because it cannot be treated. In this sense, MCI produces further uncertainty and risk and at times this meant that MCI was actively not utilised by some practitioners in the service.

A diagnosis more generally is used to mobilise action through resource allocation and treatment options (Jutel 2009, Jutel and Nettleton 2011); however, what the following extract from Consultant Psychiatrist Three highlights is that uncertainty around disease progression may have unproductive consequences for continuing the diagnosis process beyond the clinic in terms of treatment options and planning for the future. For Consultant Psychiatrist Three, an 'ideal diagnosis' or formal label is used to drive management and treatment of the condition but as they explained, this is difficult to practise when labelling patients with MCI:

> A diagnosis is given to either help the patient to understand what's going on, deal with it and plan ahead for the future and to get treatment that would normally be the reasons why we give somebody a diagnosis so you know what you're dealing with and you plan ahead and can get some treatment. With MCI is such a heterogeneous category, that some of these people may just have age related cognitive decline. Some of them maybe a bit physical health problems or medication issues so it may be just something that's static as 1 in 10 will go on to progress to AD each year, so 1 in five you'd expect half of them to go on to progress to AD but you can't say which will and which patients won't. So essentially you're giving someone a diagnosis but saying to somebody, I don't know if this'll get worse. It may become AD or not, there's no specific treatment that we can suggest other than healthy lifestyle which you would have given them anyway even if it wasn't MCI.

Navigating the borderlines of classification, which manifested at times in the label MCI was complex and uncertain since MCI does not have the ability to determine progression to AD and this impacted on the role of practitioners in the clinic. Upon diagnosis, the work of the practitioner is to provide possible treatment and to enable patients to 'plan ahead', which is compromised when employing the label MCI. There is little certainty in this label for practitioners in terms of proceeding with the process of diagnosis, and little certainty for patients in terms of prognosis (c.f. Beard and Neary 2013).

Entanglements of risk, age and cognitive deterioration

Negotiating uncertainty regarding the boundaries of classification and crafting MCI in the clinic is a complex process demonstrated by the ambivalence emergent across practitioners' accounts. This complexity, however, was not solely emblematic of the contestation around future progression to AD and therefore the meaning of diagnosis more generally (see Jutel 2009, 2015) but also about MCI's complex entanglement with age and the expansion of the disease category overall. As the following extract from an interview with Clinical Psychologist One illustrates, concerns around the label MCI stemmed from its very expansion as a formal category and the ways in which 'forgetfulness' and memory more generally are being (re) framed along medical and clinical terms:

> But we're getting more and more of that I think as people are more aware of memory and having bad memory and people think there's something wrong about that. Whereas I think in the past, so if you asked my older colleagues, one chap who recently died unfortunately, but he would, I remember a conversation with him where he was saying MCI is just a label for someone that we've [healthcare practitioners] always known about and is just an invention of the PhD industry of America.

MCI works to medicalise memory loss and becomes difficult to separate from the ageing process more generally as Consultant Clinical Psychologist One reflected on during interview, 'I don't know how much it's in some cases that MCI is part of the ageing process?'. The categorical distinction between memory loss, 'having a bad memory', and pathological decline is reconfigured with the re-categorisation of the disease as it formally classifies individuals that 'we've [healthcare practitioners] always known about'. In this sense and broadly speaking, MCI has reconfigured normative assumptions regarding cognitive decline and the ageing process. Described by Clinical Psychologist One as 'having a bad memory', by other practitioners as 'forgetfulness' (Interview Memory Nurse Three) are constructed as problematic factors linked explicitly to age and have become increasingly medicalised. A number of practitioners in the service highlighted the difficulties in negotiating this increasing medicalisation as confirmed by Consultant Clinical Psychologist One during interview:

> Mild cognitive impairment: I mean it's becoming kind of almost like a fashion word now these days isn't it everybody's talking about mild cognitive impairment … and the danger is if we pathologise it, it's a really difficult balance to strike.

This complexity also provokes tensions around the wider conditions in which cognitive deterioration is constituted. The ways in which practitioners approached uncertainty with regard to the boundaries of classification and in labelling patients with MCI relates to wider societal perceptions of the nature of growing older and of problematic ageing brains. In turn, these perceptions are fuelled by increasing efforts to medically manage the risks of developing cognitive deterioration associated with conditions such as AD (c.f. Peters and Katz 2015). As I will go on to demonstrate, contestation around MCI for practitioners was not only related to the uncertainty concerning future progression to AD but also in relation to managing the wider sociocultural discourses of age and cognitive deterioration.

When presented with borderline cases, distinguishing 'normal' ageing processes from MCI was a complex process of both identifying and accounting for risk, and negotiating the discursive constructs around what it means to age as Consultant Psychiatrist Three explained during interview:

> Mild cognitive impairment is ill-defined. There's no clear borderline between AD or MCI and ageing and sometimes the temptation is we want a diagnosis, MCI is an easy diagnosis, it's not quite AD. But, so a lot of people do get a diagnosis of MCI that may just have normal age related cognitive decline. It's more a formal diagnosis rather than just saying it's just your age which families, patients, GPs if they're worried to come to the GP and they come back 'oh this just seems to be your age'; so even though it's possibly an arbitrary distinction between early MCI and age related cognitive decline I think you might veer towards calling it MCI, it's that distinction.

As Consultant Psychiatrist Three outlined, practitioners were driven at times to formally categorise patients with MCI to discursively distinguish MCI from processes of ageing. MCI was not used solely to manage risk, it was also used as a formal diagnosis to reassure patients that it's not 'just your age'. Paradoxically, this may work to reinforce the constructed distinction between successful and unsuccessful ageing or dementia as representing a failed later life (see Gilleard and Higgs 2013, Peters and Katz 2015).

MCI was driven by social and cultural expressions in the memory service of what, or who, should be regarded as normal or pathological. These classificatory struggles were evident across practitioners' accounts as they mobilised discourses related to how cognitive deterioration and its conflation with ageing is perceived within the general population as Clinical Psychologist Two highlighted:

> I think people have this idea that they confuse getting old with somebody who has AD. I will usually spend an amount of time talking with them about trying to help them understand and make sense of, *ok we're saying there's nothing wrong but you've felt there was so why is that* and so sometimes that'll be saying to someone, *look the scores you're getting are not in the clinical range but maybe there's some maybe there's a little bit of a drop off in this compared to where you were you might have been and that may just be ageing and you may just be noticing normal ageing.*

Here, Clinical Psychologist Two described how they negotiated the discrepancy between patients' symptoms and a borderline score on a cognitive screening test. Reassuring the patient that 'there's nothing wrong' required navigating how the patient conceived the nature of growing old *without* cognitive decline. Practitioners were continually working to negotiate potential clinical risks alongside pervasive social and cultural imaginings of age and its relationship with cognitive deterioration. Consultant Psychologist One developed this further during interview when discussing how ageing is perceived in relation to labels such as MCI:

> I think that there's also you know we're inherently an ageist society and so being old is seen as the antithesis of good really so it's better to be 25 than 45 and it's better to be 45 than 65 and so on.

There is an intense classificatory struggle between how ageing is constructed as a success or failure, marked by decline in cognitive function in a wider social and cultural context where older age is not necessarily valued as the above extract highlights (see Gilleard and Higgs 2013). Yet in the memory clinics, labelling patients with MCI legitimated patient symptoms beyond that of 'normal' ageing. This reinforced the claim that positive or successful ageing is built on a discursive oxymoronic notion that to age successfully is to resist ageing (c.f. Torres and Hammarström 2009).

Constructions of cognitive deterioration and AD in classifying MCI

Alongside the entanglements of age and cognitive deterioration in constructing classification boundaries, practitioners working across the memory service also recognised that there are powerful assumptions about cognitive deterioration associated with AD that reside in the population, which have the potential to infiltrate the practices of the clinic and impact their utilisation of MCI. At times, MCI was perceived by practitioners to be less threatening for patients compared to AD, which drove how the label was employed as a means to avoid ascribing the associated 'spoiled identity' of AD as highlighted during a conversation with Consultant Psychiatrist Two:

> I think the temptation for some people is to use it [MCI] 'cause they don't want to say you've got AD'.

This was evidenced further during an interview with Memory Nurse One when she was asked to reflect on the utility of MCI as a label:

> I think it might be quite intimidating for people. I guess from my perspective when we know what it is, you know we think it sounds relatively benign compared to Alzheimer's disease but I bet if you gave somebody that diagnosis, they wouldn't like it really but if you could explain to them what it is then that's probably, I do think it is a useful diagnosis definitely.

Here, a diagnosis of MCI was at times useful for patients since its label had more 'benign' consequences than perhaps AD. As a result, this impacted how practitioners approached labelling patients with MCI. While they recognised that it may be 'intimidating' for some individuals, they argued that it could provide some 'relief' in comparison to receiving a diagnosis of AD as explained by Memory Nurse Four during interview:

> So they're given an MCI when alongside that it doesn't have the knock-on effect of if they don't have to stop driving ... so in that respect it can you know, it can be seen as a sort of relief for people.

The impact of a diagnosis of MCI is perceived to be less threatening for patients than a diagnosis of AD. AD diagnosis has anxiety provoking consequences for patients given the pervasive perceptions of loss of self and independence which circulate; driving is used here as an example. As I have shown elsewhere (Swallow 2017), pejorative views of cognitive deterioration (particularly which circulate in media discourse) associated with cognitive deterioration reinforces the need to locate, identify and manage symptoms within a clinical or medical framework particularly at earlier stages through labels such as MCI: 'problems' to be managed. This has the potential to create huge anxiety for patients which adds further complexity to the process of labelling patients with MCI, as Memory Nurse Three explains:

> The other thing which isn't helpful in the press is you see the most traumatic and difficult cases and people think that's what's going to happen to me and that's not necessarily the case ... so going back to your question about MCI it can, it can create this anxiety which is not helpful.

Negotiating the boundaries of classification involved practitioners both mobilising and accounting for risk and uncertainty while also recognising the contestation around MCI *and* managing the ways in which expectations around ageing and cognitive deterioration circulate in the wider population. Individuals experiencing cognitive deterioration may fear the 'community of otherness' that this represents through labels such as MCI or AD (Gilleard and Higgs 2013: 368, Grenier *et al.* 2017). For practitioners, MCI at times has the potential to provide a sense of relief for patients in comparison to AD and the label enabled them to avoid ascribing the 'spoiled identity' of AD (Goffman 1963). Constructing the boundaries of classification for those patients at the borderlines therefore requires not only negotiating the uncertainty around progression to AD but in working to carefully account for sociocultural discourses around age and cognitive deterioration. Constructing the boundaries of diagnosis is both material practice and dependent on its sociocultural framing which impacts how the boundaries of classification are constructed beyond the management of risk (see Jutel and Nettleton 2011, Latimer 2013).

Discussion

MCI has become a ‘matter of concern’ in a context where efforts to manage the ‘demands’ of an ageing population are dominated by (bio)medical and clinical interventions. Concurring with Lock (2013a, 2013b), uncertainty dominates understandings of and approaches towards MCI, and directly impacted how practitioners approached the label in practice. I began the article by examining how practitioners mobilised uncertainty to keep patients on in the service and at times labelled patients with MCI to account for the risk of progressing to AD in the future. Addressing the role of uncertainty in diagnostic work, this extends beyond managing the difficulties associated with predicting future progression to AD, to negotiating the uncertainties concerning the functionality of diagnosis; there are no effective treatment options, health and social care services are underfunded, and age, cognitive deterioration and AD intersect in complex ways. At times, MCI emerged as a vehicle through which uncertainty was managed; a finding which accords with Latimer’s (2013) claims that the clinic ‘thrives on the imprecise’ returning the act of decision-making to the clinic when faced with diagnostic uncertainty (p. 103). Yet, developing Latimer’s (2013) work, this mobilisation of uncertainty was not approached unequivocally by practitioners when labelling patients with MCI. For a number of practitioners, they resisted the label since there is a lack of certainty regarding disease progression as well as the fact that the label can potentially generate further uncertainty and anxiety for patients and practitioners, particularly given the lack of treatment and underfunding of care following diagnosis. Uncertainty as an enabling feature of healthcare practice and in the process of classification was therefore not approached unequivocally as demonstrated by practitioners’ ambivalence.

I developed the analysis in the second section of the article to highlight how the bounds of classification are socially and discursively constituted as ageing becomes (re)cast in medical and clinical terms (see Brown *et al.* 2011, Jutel 2015). Emergent across practitioners’ accounts was the fact that ageing is problematised through the expansion of the disease category to include MCI and practitioners worked to contain this complexity in the clinic. The process of classification therefore required practitioners to deconstruct and interrogate the sociocultural boundaries of what/who should be labelled as pathological with a specific focus on how this relates to ideas around ageing and ‘risky’ ageing brains (see Peters and Katz 2015). Classifying MCI also required careful negotiation of the wider social context in which ageing, cognitive deterioration *and* AD intersect. At times, practitioners classified patients with MCI to actively differentiate it from processes of ageing in order to reassure patients. The extent to which this has the potential to *reinforce* the discursive boundaries around successful and unsuccessful ageing requires further investigation (see Gilleard and Higgs 2013, Grenier *et al.* 2017, Peters and Katz 2015). As I demonstrated in the third section, MCI was also utilised as a means to account for cognitive deterioration without employing the label AD as it was seen to be less anxiety provoking for patients given the imaginaries of decline that circulate, for example around loss of independence and self. Classification was therefore constituted through the efforts to manage and make sense of risk, and also account for the complex relationship between age, cognitive deterioration and AD.

Building on literature within the sociology of diagnosis, this article has shown that uncertainty produced by the re-categorisation of AD and the scepticism around the condition as a discrete entity (c.f. Rafalovich 2005), however, are not disposed of by practitioners but became part of the process of classification (and resisting classification) when framed within its broader social context (see Armstrong and Hilton 2014). The interpretational process of negotiating the boundaries around ‘normal’ ageing and pathological deterioration also required practitioners to account for the possible consequences of classification for patients and for their own professional practice. At times the functionality of MCI (see Timmermans and Buchbinder 2010) was called into question and practitioners described keeping patients on in the memory service without employing a label. This article has shown that practitioners' accounts of MCI are therefore diverse and at times competing as an intermediate category it is both utilised to resolve uncertainty (practitioners worked to 'fold in' to a diagnostic category, see Timmermans and Buchbinder 2010) and at times was actively avoided in order to contain further ambiguity. This sense of ambivalence around resolving uncertainty is entwined with a wider political and economic context of uncertainty concerning the availability of resources post-diagnosis, reorganisation of health and social care services, and subsequent inequalities regarding access to care for patients at the borderlines.

Further research is required to capture the moments at which a diagnosis of MCI is reached in practice in order to more thoroughly analyse how the intersections between age, cognitive deterioration and AD circulate during interactions and their implications for clinical practice.

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Note

1 In the memory service, psychiatrists and psychologists are the only practitioners involved in adjudicating a diagnosis and communicating this to patients. However, memory nurses carry out the majority of the screening and diagnostic tests and play an important role in reaching a diagnostic decision and in monitoring patients within the service.

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