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Abstract

Background Communication of Mild Cognitive Impairment (MCI) diagnoses is challenging due to its heterogeneity and unclear prognosis.

Aim To identify how MCI is communicated and to explore the relationship with patient and companion understanding.

Method Conversation analysis identified whether MCI was named and explained in 43 video recorded diagnosis feedback meetings. Afterwards, patients and companions were asked to name the diagnosis to assess understanding.

Results MCI was not named in 21% meetings. Symptoms were explained as (1) a result of vascular conditions (49%), (2) a stage between normal ageing and dementia (30%), or (3) caused by psychological factors (21%). 54% of prognosis discussions included mention of dementia. There was no association between symptom explanations and whether prognosis discussions included dementia. 57% patients and 37% companions reported not having or not knowing their diagnosis after the meeting. They were more likely to report MCI when prognosis discussions included dementia.

Conclusions Doctors offer three different explanations of MCI to patients. The increased risk of dementia was not discussed in half the diagnostic feedback meetings. This is likely to reflect the heterogeneity in the definition, cause and likely prognosis of MCI presentations. Clearer and more consistent communication, particularly about the increased risk of dementia, may increase patient understanding and enable lifestyle changes to prevent some people progressing to dementia.

Key words: Mild Cognitive Impairment, Vascular Cognitive Impairment, Communication, Diagnosis, Prognosis, Understanding

Key points:

- Mild Cognitive Impairment (MCI) is a heterogenous and debated clinical construct, which is reflected in wide variation in how it is communicated to patients.
- There are three different explanations of MCI communicated to patients: (1) impairments due to vascular damage, (2) impairments as a stage between ageing and dementia, and (3) impairments caused by psychological factors.
- 54% of diagnosis discussions included dementia as a possibility for the future.

- Patients and companions were more likely to report MCI as the diagnosis when dementia was included in prognosis discussions.

Introduction

Sharing a diagnosis of Mild Cognitive Impairment (MCI) could enable people to manage their symptoms and make lifestyle changes that may prevent dementia[1]. Modifiable risk factors for progression include diabetes, neuropsychiatric symptoms and low folate, indicating that dietary or psychological interventions may have an impact[2]. There is an estimated 15-20% prevalence of MCI in the over 60s and a rate of progression to dementia from 8-15% per year[3].

However, MCI has a reputation as an unstable or heterogenous diagnosis, which is attributed to uncertainty about its causes and subtypes[4,5]. MCI has evolved from describing an ambiguous state between normal ageing and dementia to representing an effort to discriminate between different disease processes with different prognoses and treatments[3,6]. Research has identified varying features such as amnestic vs non-amnestic symptoms, single vs multiple cognitive domains, vascular vs non-vascular causes, prognostic indicators, and biomarkers[3,7-9]. Additionally, MCI prognoses have been demonstrated to vary: from progression to dementia to reversal of symptoms[2,10].

This heterogeneity has an impact on communication of MCI diagnoses to patients[11,12]. Clinicians report discussing prognosis at MCI diagnosis 60-80% of the time[13,14]. Patients experience MCI with a mixture of relief in not having dementia

and frustration about the ambiguity surrounding the diagnosis[15,16], with patient explanations of MCI ranging from 'not dementia' to mild Alzheimer's disease[17]. This confusion may be caused by differences in diagnostic communication.

Given the heterogeneity of MCI, clinicians may be altering their diagnostic communication according to their judgement of cause of the patient's symptoms and the likelihood of progression to dementia. This could affect the information patients take on board. The aim of this study was to (1) identify how doctors communicate a diagnosis of MCI and its prognosis, and (2) explore the relationship between how MCI is communicated and patient and companion understanding.

Methods

This research is part of an NIHR RfPB funded study exploring communication in memory clinics (ShareD, 'Shared decision making in mild to moderate dementia' PB-PG-1111-26063), with results published elsewhere[11,18,19]. Camden and Islington Research Ethics Committee approved the study (REF: 13/LO/1309).

Data Collection

The data consists of video recordings of diagnosis feedback meetings that took place across 9 UK-based secondary care memory clinics across rural and urban settings. Diagnostic feedback meetings were video recorded and transcribed. The clinic structures and recruitment methods have been described in previous ShareD publications[11,18,19].

Patient and companion understanding

Patients and companions were asked "Did the doctor give a name (or diagnosis) for your memory problem? If so, what?" The responses to this question were used to assess understanding of the diagnosis.

After each meeting, the doctor completed a form indicating the person's diagnosis. The cases where the doctor indicated a diagnosis of 'Mild Cognitive Impairment' (MCI) or 'Vascular Cognitive Impairment' (VCI) were analysed.

Data Analysis

We used conversation analysis (CA), an in-depth, qualitative method to micro-analyse communication[20]. Excerpts where diagnosis was discussed were identified from watching the recordings and transcribed using CA methods[21]. This enabled

description of communication practices doctors use to deliver MCI diagnosis. These practices were then coded to allow quantitative descriptions. Fisher's Exact test explored relationships between practices and patient and companion understanding.

Validity was addressed through repeated analysis within and external to the research team[22]. The inclusion of data from different doctors in a variety of clinics, as well as comparison with studies of diagnosis deliveries in other settings, enhances reliability[23].

Results

Participant information can be found in Table 1. The consent rate for clinicians participating in ShareD was 88%. This dataset includes 12 doctors from 6 memory clinics. There was a median of 2 patients per doctor, ranging from 1 to 15.

[INSERT TABLE 1 HERE]

Of 215 patient participants recruited to ShareD (consent rate 51%), 47 received diagnoses of MCI or VCI. The remaining patients received diagnoses of dementia (n=101), mood related diagnoses such as depression or anxiety (n=21), were referred for further testing (n=34) or did not receive a diagnosis (n=22), with doctors advising re-referral for tests at a later date if symptoms worsened. Forty-three videos are included in this data set, the remaining 4 had technical difficulties with their

recordings and could not be included. The mean Addenbrooke's Cognitive Examination III (ACE-III)[24] test score for participants with MCI or VCI diagnoses was 83 (range=60-94, SD=8.5).

In 5 meetings patients attended without a companion. Twenty-six patients attended with a spouse/partner, 6 with a child/child-in-law, 3 with a friend, 1 with a sibling and 2 identified as 'other'.

Communication of MCI diagnosis

Communication of diagnosis varied. Figure 1 shows a flow of the diagnostic information given to patients.

[INSERT FIGURE 1 HERE]

Selected extracts are presented below. CA transcription symbols have been removed; detailed transcripts and further examples are available from the authors. The numbers in brackets represent timed pauses in seconds and squared brackets represent overlapping speech.

Diagnosis communicated to patients and explanations for symptoms

In all but one case, the diagnosis was presented explicitly as 'not dementia'.

Extract 1

DR: but as I said **it's not severe enough to be dementia.** It's- it's not that (0.3) but **we call it mild cognitive impairment**.

MCI or VCI was explicitly named in 34/43 meetings (79%, MCI=29, VCI=5), as in Extract 1. In 13/29 meetings where MCI was named, doctors explained MCI as a stage between 'normal' ageing and dementia.

Extract 2

DR: so we are on a spectrum of normal (0.2) memory and then with age we forget so there's some age related changes and then eventually there is dementia. But **in between that age related change and dementia there's a grey sort of area** where (0.2) you have what we call as mild (0.2) cognitive impairment.

In the 9 meetings where a diagnosis was not named, explanations were given for patient symptoms.

In 6 of these meetings symptoms were attributed to vascular disease.

Extract 3

DR: I think you have got some (0.4) you know (0.2) changes in memory and language (0.4) because of **age related change to the- to the blood vessels in the brain**

Vascular disease was also presented as the primary explanation of symptoms in 10/29 of the meetings where MCI was named and all the meetings where VCI was named (5/5).

For 5 of the meetings where MCI was named and 3 where no diagnosis was named, symptoms were explained as a result of low mood or anxiety.

Extract 4

DR: I think you've got (0.3) some cognitive impairment
PT: okay
DR: um so (.) pr- a problem with memory or thinking
(.)
DR: and I think (.) the (0.7) y- the cause of that- we- so we often have this (0.4) what they call a diagnosis of mild cognitive impairment
(0.6)
DR: the cause of that can be (.) lots of things.
(.)
DR: so age plays a part
PT: mm

(0.3)

DR: um (.) certainly **things like anxiety can [play a part]**

PT: [mm]

(0.6)

DR: and sometimes some of that can be unconscious (.) you're not aware of it?

(0.8)

DR: um (1.4) you know **it may well be that there's (0.4) a degree of unconscious anxiety about things** about the future for [example]

PT: [mhm]

(.)

DR: that's play- having a- **an effect on your attention on your ability to concentrate and a- and attend to things and that then has a knock on effect on memory**

In one case, the doctor attributed the patient's MCI to alcoholism.

The diagnoses and explanations were categorised for quantitative analysis. The first categorisation was whether MCI/VCI was named (n=34, 79%) or not (n=9, 21%). The second categorisation was the explanation for symptoms: (1) impairment caused by vascular conditions (n=21, 49%); (2) impairment as a stage between age and dementia (n=13, 30%); or (3) impairment caused by mood or alcoholism (n=9, 21%).

Prognosis discussions

Prognosis was discussed in all but one of the meetings. In the latter, the patient was highly anxious and the discussion focused on management of anxiety.

In 23 meetings (54%) prognosis discussions included an explicit indication that dementia was a possibility.

Extract 5

DR: some people (0.2) with mild cognitive impairment do (0.2) **get (0.4) worse (0.4) eventually and get a dementia**

In most of these cases dementia was discussed as a possibility in the future, but in 7 cases the doctors indicated the possibility of the patient having dementia already.

Extract 6

DR: you know **we could be seeing the very early signs of something like a (0.2) a vascular dementia**

In the remaining 46% (20/43) meetings doctors implied that the condition can progress but did not mention dementia. In 13 of these meetings (30% of total) doctors stated an expectation that the patient's condition would not get worse.

Extract 8

DR: the brain's a bit like that you know once a certain amount
of change has happened it can't (0.2) get older [if you] know
PT: [mm]
DR: what I mean
PT: ye[ah]
DR: [th]e change [is] already there
PT: [yeah]
PT: yeah
DR: and so generally (0.4) you know (0.2) **things should settle down and stay (.) pretty much (0.4) at the level that they're at now**

Prognosis was also coded as to whether dementia was mentioned as a possibility for the future (n=23, 53%) or not (n=20, 47%). This was not associated with whether a diagnosis was named (Fisher's exact = .26) or the explanation given to the patient (Fisher's exact = .15) (see Figure 1).

In 38 prognosis discussions (88%) doctors spoke about lifestyle modifications that could deter progression, such as stopping smoking or increasing exercise and social activities.

Extract 9

DR: **whatever is good for your heart is good for your brain**
CR: yeah

(0.3)

DR: so (0.3) m i- i- some mild moderate exercise (.) walking gardening

PT: hm hm

(0.3)

DR: that's good (0.3) healthy diet (0.5) u:m (.) hydration

Medication to prevent progression was discussed in 7 meetings (16%), specifically continuing/prescribing cardiovascular medications to prevent more vascular damage (4/7), reducing high doses of medication (2/7) and prescribing medication for anxiety (1/7). Eight patients (19%) were directed towards available research projects.

Patient and companion understanding

Patients and companions were asked to report their diagnosis (recorded immediately after the diagnosis meeting) to illustrate understanding. These showed some discrepancy with the diagnosis named (see Table 2).

[INSERT TABLE 2 HERE]

Seventeen of the 40 patients (43%) and 19/30 companions (63%) who answered the diagnosis question reported the same diagnosis or explanation of symptoms as the doctor. Of the patients who were told they had MCI, 10/29 (38%) and 12/27 companions (44%) reported MCI. Of the patients who were told they had VCI, 3/5 patients and 4/5 companions reported vascular problems as the diagnosis.

Of the 9 patients who were given an explanation of symptoms without a specific diagnostic label, 2 patient-companion dyads reported the same cause (1 age-related, 1 vascular).

Both patients and companions were more likely to report MCI or VCI as the diagnosis when these diagnoses were named by the doctor (Fisher's exact = .012 and .00 respectively).

There was a significant association between whether prognosis included dementia and patient and companion reported diagnoses (Fisher's exact = 0.004 and 0.018). In all cases where patients reported MCI as their diagnosis (and in all but 1 where companions reported MCI), dementia was mentioned as a possibility in the future.

Discussion

All the patients in this study had a diagnosis of MCI/VCI, but the communication of the diagnostic label, explanation of symptoms and likely prognosis varied. Doctors appeared to categorise patients into different subtypes of MCI in how they explained symptoms. This was not related to whether dementia was discussed as a possible prognosis. Nearly half of prognosis discussions did not refer to dementia and 30%

explicitly stated an expectation that MCI would not progress to dementia. Only 38% and 44% of patients and companions named their diagnosis as MCI after the meeting. This was more likely to occur when MCI was named to the patient and prognosis discussions included dementia.

Variation in causal explanations reflecting doctor beliefs about MCI etiology

There was a clear range in how doctors explained MCI symptoms: varying between explanations of MCI as a result of vascular damage, MCI as a stage between cognitive ageing and dementia, and MCI caused by mood or anxiety. In differentiating between the first two types doctors may be speaking to a distinction between non-vascular, pre-Alzheimer's MCI and MCI (or VCI) due to vascular pathology, which is well defined elsewhere[9]. That the MCI/VCI label was not used in 20% of the meetings may reflect a reluctance to use the diagnosis stemming from beliefs about its ambiguity. These views were discussed in focus groups with these clinicians as part of the ShareD project[11] and reflect clinicians reports of diagnostic value[13,25].

It is noteworthy that 21% patients were given an MCI diagnosis attributed to mood, while 10% patients in wider dataset were given non-MCI diagnoses of depression or anxiety. There is a complex relationship between anxiety, depression, MCI and dementia, with some suggesting a continuum of symptoms and others identifying

mood disturbance as a risk factor for progression to dementia[2,26-28]. The variation in prognostic communication may therefore reflect whether doctors identify depression or anxiety as (1) manifesting through memory problems (i.e. as a 'pseudodementia') or (2) as a precursor to dementia. When giving an MCI diagnosis explained as a mood disorder, it may be that doctors are unclear as to which of these options the patient has. There is confusion around the relationship between these conditions, with evidence that people with MCI and co-morbid psychiatric conditions are more likely to revert to normal cognition than progress to dementia[29], but depression also being classed as a dementia risk factor[30]. The doctors in this study more often discussed dementia as a possibility in MCI attributed to mood than with MCI attributable to vascular changes. While it may have been expected that the variation in prognosis discussions would depend on clinical judgement of the etiology for the patient's MCI and the potential for reversibility, there was no association between the diagnosis labels or explanations presented to patients and whether dementia was discussed.

Patient experience and understanding as a result of diagnostic communication

In previous work patients and companions experience MCI diagnoses as confusing and frustrating[31]. The varying patient and companion reports on diagnosis demonstrate confusion around MCI that is present in other studies[32]. "No problem" and "not dementia" were frequently reported regardless of whether a label was used and the explanation given, which may reflect the fact that the doctors explicitly

told the patients they did not have dementia in all but one consultation. While this may later be contradicted (for example in Extract 6 where the doctors says the patient's symptoms may be the start of vascular dementia), emphasising the absence of dementia at the beginning of diagnosis discussions may be distracting from other aspects of diagnostic information that doctors wish to convey.

While doctors using the labels MCI or VCI naturally led to more people reporting MCI/VCI as their diagnosis, 62% of patients and 56% of companions who were told MCI did not report this immediately after the meeting. This may reflect studies demonstrating that people with MCI conceptualise their condition according to lifestyle rather than biological factors[33]. The low reporting of diagnosis labels may also reflect previously reported mistrust of MCI diagnoses, with many believing their symptoms are more severe than MCI suggests[16]. MCI labels were reported more often when doctors included dementia in prognostic discussions, which suggests the diagnosis is better understood when it is framed as a "pre-dementia" state.

Discussion of increased dementia risk at MCI diagnosis

It has been argued that the primary reason to disclose an MCI diagnosis is to set appropriate expectations for the future[1]. However, dementia was not mentioned explicitly as a possibility in 46% of meetings and in 30% of meetings doctors expressed an expectation the patient's condition would not progress. These findings,

while comparable to other studies[13], conflict with MCI guidelines that recommend clinicians discuss future planning with patients at diagnosis[34,35].

Our previous work on dementia diagnosis found progression was only explicitly mentioned in 38% of meetings[18]. Doctors reported a need to balance hope with bad news of dementia, leading to an emphasis on medication and support over discussions of the future[11]. This is mirrored in MCI diagnosis, where 88% of the consultations contained discussions of modifiable lifestyle factors that may ameliorate symptoms, and 16% discussed medication having preventative effects. While evidence suggests there are modifiable risk factors for progression to dementia[2,36-37], the emphasis on lifestyle changes and medication while downplaying progression may lead to unrealistic expectations. People with MCI have been shown to have lower affect than patients with early dementia, often stemming from anxiety for the future[38], and therefore a balance of realistic and positive prognostic discussions is particularly important.

Strengths and limitations: scope for future research

The use of CA as a rigorous micro-analytic method of exploring MCI diagnosis delivery in practice is a strength of this study. The video recordings were collected from 12 doctors across three UK sites in two different geographical areas enhancing generalisability. A limitation is that it was not possible to verify the diagnoses

reported, future longitudinal research where accuracy of clinical diagnosis is ascertained will be beneficial in further exploring the issues raised in this study. The fact that 15 videos came from one doctor may skew our findings, and also reflects a potential bias according to doctor likelihood to diagnose MCI which was not captured in this study. Additionally, MCI is a heterogenous diagnosis with complicating factors in the choice of communication that we did not explore. For example, future research could examine the effect of doctor perspectives on subtype and prognosis. There are also other factors that may affect patient and companion understanding and reporting of their diagnosis: future research could explore whether clearer communication about future risk of dementia motivates behaviour change in relation to modifiable risk factors such as smoking, alcohol, hypertension and physical activity.

Conclusion

This conversation analysis of MCI diagnosis delivery has shown how varying clinician perspectives on the cause and prognosis of MCI may result in mixed signals to patients. While further research on the accuracy, progression, and patient understanding of MCI diagnoses in practice is needed to provide definitive guidance, preliminary recommendations can be suggested from these findings. The variation in diagnostic information communicated to patients is likely to be a reflection of the heterogeneity of MCI as considered by clinician assessment of each individual

patient, i.e. either as being in a pre-dementia stage of cognitive decline or a potentially reversible condition of cognitive impairment. It may be that a consensus definition of MCI would lead to more consistent communication thus increasing patient understanding. Clearer communication specifically about the risk of developing dementia is also necessary. Evidence suggests that lifestyle changes may reduce the risk of progression to dementia. Prognostic information would therefore be crucial to empower patients to implement such changes. Co-production of clinical guidelines or advice, guided by further research, would be beneficial.

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Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Table 1: Participant Characteristics

Characteristics	
Doctors	N=12
Gender	
Female	6
Male	6
Age	
35-44	7
45-54	2
55-64	3
Ethnicity	
White British	9
Indian	2
Asian/Asian British	1
Doctor Type	
Psychiatrist	8
Geriatrician	3
Specialty doctor	1

Site	
London	4
Devon	8
Patients	N=43
Gender	
Female	13
Male	30
Age	Mean: 75.8, SD=8.3, range 56-93
Ethnicity	
White British	39
Indian	1
Bangladeshi	1
Diagnosis	
MCI	38
VCI	5
ACEIII (n=40)	mean=83/100, SD=8.4, range 60-94
MMSE (n=1)	29/30

ElCog (n=1)	84/100
TICS (n=1)	33/51
<u>Carers</u>	N=38
Gender	
Female	27
Male	11
Age	Mean=66.2, SD=14, range 34-88
Ethnicity	
White British	36
Indian	1
Bangladeshi	1
Relationship to Patient	
Spouse/Partner	26
Child/Child-in-law	6
Friend	3
Sibling	1
Other	2

Table 2: Named and Reported Diagnoses

Diagnosis named by doctor (explanation given)	**Patient reported diagnosis**	**Companion reported diagnosis**
MCI diagnosis (stage between 'normal' ageing and dementia, n=12)	MCI n=4 Age n=2 'Don't know' n=2 'No problem' n=4 Missing n=1	MCI n=4 Age n=3 'No problem' n=3 Missing n=3
VCI (vascular disease, n=5)	Vascular disease n=3 'Not dementia' n=2	Vascular disease n=4 Missing n=1
MCI (vascular disease, n=10)	MCI n=5 Age n=2 Vascular disease n=2 'Don't know' n=1	MCI n=6 No companion n=2 Missing n=2
MCI (low mood or anxiety, n=5)	MCI n=2 Age n=2 'Don't know' n=1	MCI n=2 'No problem' n=2 Missing n=1
MCI (alcohol, n=1)	Alcohol n=1	Alcohol n=1
No diagnosis (vascular disease, n=6)	Vascular disease n=2 Age n=1 No problem n=2 Missing n=1	Vascular disease n=1 Age n=1 No problem n=1 No companion n=2

		Missing n=1
No diagnosis (low mood or anxiety, n=3)	Vascular changes n=1 'No problem' n=1 Missing n=1	Vascular disease n=1 Age n=1 No companion n=1

Figure 1: Flow of Diagnostic Information