



Is a Diagnosis of Mild Cognitive Impairment a Blessing or a Curse?

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Background: What is MCI?

- First appearances in the clinical literature in 1990s
- “[A] boundary or transitional state between normal aging and dementia” (Petersen et al. 1999, p. 303)
- But – not everyone develops dementia
- Does not affect daily functioning – though more complex activities may be affected

Controversies

- Several diagnostic criteria have been proposed, with different levels of subtyping.
- Prevalence rates between 3 and 42% (Ward et al. 2012) – one consequence of divergent criteria / operationalisation?
- What exactly *is* ‘normal aging’ anyway?



Research aims: part 1

- To synthesise the existing qualitative literature on people's experiences of being diagnosed, and living with, a MCI diagnosis
 - How do people make sense of the label?
 - What are the psychosocial implications of being diagnosed?
- Metasynthesis: A qualitative approach to putting studies together



Living With Ambiguity: A Metasynthesis of Qualitative Research on Mild Cognitive Impairment

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Purpose of the study: Mild Cognitive Impairment (MCI) is a diagnosis proposed to describe an intermediate state between normal cognitive aging and dementia. MCI has been criticised for its conceptual fuzziness, its ambiguous relationship to dementia, and the tension it creates between medical and sociological understandings of “normal aging”

Findings

- Two overarching, conceptual themes developed:
 1. 'MCI and myself in time'
 - Past
 - Present
 - Future
 2. 'Living with ambiguity'
 - 'normal', 'non-normal', or 'pathological'?
 - Uncertainty in diagnosis and information

Theme 2(i): Uncertainty of diagnosis / info

- People were told about MCI in lots of different ways throughout the literature.
- “My feeling is there is a lot of guesswork involved and that people don’t really know. Do you have early-stage Alzheimer’s? Do you have MCI? Is there a difference? [...] It’s like trying to make sense of nonsense” (Beard & Neary, 2013, p. 138).

Theme 2(ii): ‘normal’, ‘non-normal’, or ‘pathological’?

- People questioned whether MCI was a ‘real’ problem, or ‘just part of aging’.
- “Well... I think I was relieved [...] I was concerned probably like everyone else would [be], that I had Alzheimer’s, and then he said, ‘you don’t have Alzheimer’s,’ and you know that’s like taking a cloud off your shoulder [...] so giving it a title, you can call it anything you want, but it’s not Alzheimer’s, so I can live with it” (Lingler et al. 2006, p. 795-796)

Research aims: Part 2

- Collaborate with people who receive an MCI diagnosis to understand the impact on them and their families over time.
- Measures: MoCA, HADS, QoL-AD, FAI, brief COPE
- Identify areas where they would like more information/support/assistance
- Examine role for technology in enabling people to live as well as possible

Participants

Name	Age	Sex	Education	MoCA score
Alison	69	F	High school	26
Steven	60	M	High school	26
Richard	93	M	Higher degree	14
Suzie	80	F	High school	21
Andrea	76	F	High school	25
Dave	63	M	High school	30
Mary	84	F	First degree	23
Bill	83	M	High school	18
Joyce	75	F	High school	24
	75.7 (range 60-93)	5 F 4 M		Range 14-30

Fears

- Steven: “Right well what I did say was I said “if you tell me I’ve got Alzheimer’s... I’m not long for this world” I said “because I can’t cope with that”
- Andrea: “he shows me the diagram he says ‘your brain’s alright – and believe me you haven’t got cancer’ so I says ‘you sure? That’s what’s been frightening me, losing it’ so he says ‘no love’ he says ‘no’ he says ‘I think you’ve got a touch of Alzheimer’s’. (long pause).

What does Mild Cognitive Impairment mean to you?

- Steven: “I don’t know. I don’t know, I was relieved, I was relieved when I came out but I just had that... that niggle that... maybe... I don’t think he did, I think he told me the truth, in fact I know he would I mean he... um... because he didn’t say “you’ve just got a *mild* Alzheimer’s” or something, he said “you’ve definitely not got Alzheimer’s” so by that I took him on his word but... it was because I’d... I’d told the doctor [suicidal thoughts] and obviously she she could tell them... er I just wondered whether they’d decided oh, we’ll not tell him it’s Alzheimer’s, we’ll tell him it’s something else y’know but obviously they didn’t do that, it’s just me... wondering”

What does Mild Cognitive Impairment mean to you?

- Suzie: “I don’t know. I don’t feel as if I’m stupid or anything like that (I: no). I try to still do you know things like that to keep me going but when you don’t go out very often and see people I think it sort of comes back on you somehow.”
- Joyce: I haven’t a clue. I’ll ask our Janet, she’ll explain it all [to interviewer] what does it mean?”
- Andrea: “I don’t understand it. I only think I... I can’t remember things as you know I’ve never remembered names from being way back.”

Relationship to 'normal' ageing

- Mary: “I visited er a friend who was in a nursing home the other day – I go about once a fortnight to see her, and I’m given a lift by another mutual friend – and I told this other mutual friend who’s almost my age (84) about this and she *roared* with laughter and said “what on earth are you doing that for?!” She thought it was *outrageous* that I should um be going to a memory clinic. Um... she said “we’re all like this, we all forget” um... and up to a point she’s right ((both laugh)) er... but she thought I was being pushed I think to go and see them. She was very sympathetic ((long pause))”

Reaction to diagnosis

- Alison: “Yeah, yeah, er... it just I don’t know. I don’t know how to cope with it I... I thought at one point I were gonna take some tablets I have said this to the doctor I’d take some tablets and then I thought: who’s gonna find me? I don’t want them finding me. I tried to work out so nobody’d have to find me but they *do*, don’t they?”

Post-diagnosis

- Suzie: “It’s annoying when I can’t remember things, I get cross with myself cause I feel like I ought to be able to. Some days are worse than others, some days I can remember everything. It’s just the same. It would be lovely if there were a tablet that you could take that sort of made you like you used to be but I don’t suppose it will ever be made.”
- Mary: “I thought if I could get some help it would be a very good thing. Er... but er there doesn’t seem to be any. Er... not that I quite knew what I was expecting but I certainly don’t want to be a nuisance.”

Conclusions

- MCI diagnosis as 'double-edged sword':
 - Benefits: Earlier intervention, support, self-management, legitimacy of medical label
 - Drawbacks: Ambiguity of label; stigmatising of older age?
- Important to understand clinical communication around MCI
- People want to understand what to expect, how to access advice and support, how to make plans for the future

- Is a diagnosis of MCI a blessing or a curse?