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## Living with stable MCI: Experiences among 17 individuals evaluated at a memory clinic

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**Objectives:** Mild cognitive impairment (MCI) is a state of mildly impaired cognitive functioning but with an intact capability of performing basic daily activities. Few studies have targeted personal narratives from persons living with MCI, the major focus in this study is directed to methods for better predictions of the likelihood for conversion to dementia. This study directly explores experiences among individuals who have lived with MCI over seven years without converting to dementia.

**Methods:** Seventeen individuals, who had been diagnosed with MCI across four occasions over a seven-year period at a memory clinic, were interviewed at a single occasion about their experiences of living with MCI, life events, stress, coping, psychosocial resources, and lifestyle behaviors.

**Results:** Thematic analysis of the transcripts of the interviews resulted in themes revolving around the life situation and events related to the first visit at the memory clinic, coping with lower cognitive capacity with the aim of enhancing quality of life, and worries about dementia and further cognitive deteriorations.

**Conclusion:** The participants' experiences of living with MCI indicate that issues and changes in life situations such as long-term stress, retirement, loss of relatives, perceived heritability of dementia, needs to be understood in the context of the individual's understanding and interpretation of their everyday cognitive functioning. Also, supportive long-term contacts with the specialist care unit were vital for creating a personal understanding of MCI. Addressing the intra-personal dynamics of cognitive functioning in the boundary between normal and pathological cognitive aging can also improve diagnostic accuracy.

**Keywords:** mild cognitive impairment; heritability; adjustment; stress; support

Mild cognitive impairment (MCI) is a state of mildly impaired cognitive functioning but with an intact capability of performing basic daily activities (Artero, Petersen, Touchon, & Ritchie, 2006). The consequence of these relatively liberal inclusion criteria is a heterogeneous group of individuals. Some can actually represent a healthy aging group, others remain stable in their MCI diagnosis, and some will later convert to dementia. Although the expected pattern of progress involves a preclinical stage of reduced cognitive functioning, further deteriorated cognitive health, and finally a dementia diagnosis, the conversion rate from MCI to dementia diagnosis varies from 10% to 40% per year, leaving a substantial portion of MCI individuals that stay stable over long periods of time (Geslani, Tierney, Herrmann, & Szalai, 2005; Mitchell & Shiri-Feshki, 2009).

A variety of predictors and biomarkers of progression from MCI to dementia have been identified ranging from cerebrospinal fluid (i.e. Bennett, Schneider, Bienias, Evans, & Wilson, 2005; Mattsson et al., 2009), brain volumetric (Eckerström et al., 2008) cognitive (i.e. Gomar, Bobes-Bascaran, Conejero-Goldberg, Davies, & Goldberg, 2011; Nordlund et al., 2008) markers to psychosocial risk factors such as poor social network (Fratiglioni, Wang, Ericsson, Maytan, & Winblad, 2000), and more temporal as well

as distal stress (Johansson et al., 2010; Lind, Edman, Nordlund, Olsson, & Wallin, 2007).

Using a qualitative study approach, Charles, Bouby-Serieys, Thomas, and Clement (2006) asked principle caregivers to report life events that they considered may have had a significant role for the onset of dementia. Potential events reported were categorized into four distinct life-event related categories: loss, repeated or prolonged stress, psycho-traumatism, and depression-inducing events. Among the 65% who suspected a relationship between dementia onset and these events, the following specific events were reported: spouse's death (15%), parent's death (15%), family difficulty (10%), anesthesia (8%), child's death (4%), somatic disturbance (4%), depression (4%), retirement (4%), etc. Among all the reasons that caregivers assumed to be of relevance, 83% were connected with prolonged stress and 39% with a psycho-traumatic event that were likely to induce depression. Although cautious in interpreting data in terms of causality, the authors conclude that overall stress and stressful events may be potential triggers of silent ongoing neuropathological processes. Above all, the study implies that individuals create unique and personal understanding of dementia in their search for the meaning and personal understanding of the onset and disease progression.

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A range of psychological, psychosocial, and health-related factors are associated with the progression of MCI. Less is known concerning protective factors related to the stability and maintenance of cognitive health. Brain reserve and cognitive reserve have been shown to be protective for time to dementia onset, but there may be other protective factors related to the stability of MCI. For instance, more social contacts were related to less cognitive impairment across a 12-year period, also when initial cognitive performance, health, functional disability, and depression were controlled for (Bassuk, Glass, & Berkman, 1999). The pattern of psychosocial conditions as expressed in coping strategies and well-being in MCI patients was studied by McIlvane, Popa, Robinson, Houseweart, and Haley (2008) who identified a variety of coping strategies categorized as 'emotion-focused' (acceptance and use of emotional support), problem focused (planning and taking action to improve the situation) or dysfunctional (including self-blame and denial). Interestingly, emotion and problem-focused coping strategies were used more commonly than dysfunctional ones. Such findings indicate that psychosocial conditions can be related to cognitive health in old age, and motivate the study of the role these conditions may have in preventing MCI individuals from converting to dementia.

A route to improve our understanding of the contribution of risk and protective factors for the onset of dementia and later progression is to actually accumulate narratives from individuals in which these factors can be observed and interpreted in the everyday life context. In a recent review, including 21 studies of MCI patient's and carer's experiences of living with MCI, the results indicated a need of better information, psychosocial support and a closer interaction between the patient and carers, and social contacts (Dean & Wilcox, 2012). Likewise, Lingler et al. (2006) found in their interview study of 12 individuals with MCI that understanding and coming to terms with their situation constituted fundamental aspects of living with MCI. In assigning meaning, prognosis, expectations of normal aging, and also personal experience with dementia were central aspects. Furthermore, Lingler et al. called for an investigation of living with MCI over a longer time period. What happens to MCI individuals who do not convert? What does the diagnosis mean, does it become less dramatic? How do family and friends act and react? So far, very few studies have focused on experienced intra-individual scenarios, including what the 'MCI-label' means to the individual and how it may affect their lives.

The purpose of the present cross-sectional study was to explore personal experiences in individuals who were evaluated for potential dementia but found not to meet the criteria for a dementia diagnosis and who remained as MCI cases over a seven-year period. More specifically the aim was to gain a better understanding of how individuals comprehend and cope with various stressors evoked by their compromised cognitive health

and the everyday life challenges that may exceed their actual coping resources.

## Method

### Sample

Participants were 17 individuals (11 men) aged 57–86 years old with a mean age of 72 years who had met the criteria for MCIs over at least seven years and across four biannual clinical investigations. All participants resided in their own homes.

Participants were recruited from the longitudinal Gothenburg MCI-study starting in 1999 with an overarching aim of identifying neurodegenerative, vascular, and stress-related disorders in preclinical dementia. In this study a total of 30 individuals met the inclusion criteria of being stable MCI over a time period of *ca* seven years, attending a minimum of four clinical examinations occasions. These individuals received a quest of participating in the study per mail and 20 accepted the invitation. The MCI diagnosis was based on medical history and a classification of two or three according to the Global Deterioration Scale (GDS; Reisberg, Ferris, de Leon, & Crook, 1988). The rating is conducted by physicians at the clinic and is based on an evaluation of cognitive symptoms drawn from the executive symptoms interview: I-Flex, Mini Mental State Examination (MMSE; M.F. Folstein, S.E. Folstein, & McHugh, 1975), and the Clinical Dementia Rating scale (CDR; Morris, 1997). GDS stage 2 is comparable to subjective cognitive impairment and  $STEP = 0.5$ ,  $I-Flex < 3$ ,  $MMSE \geq 28$ , and  $CDR$  sum of boxes  $\leq 0.5$ . GDS stage 3 required the following outcomes  $STEP = 1$ ,  $I-Flex < 3$ ,  $MMSE \leq 27$  and  $\geq 25$ , and  $CDR$  sum of boxes  $\leq 1.5$ . The inclusion of individuals with GDS 2 or GDS 3 status across the four clinical investigation occasions implies an extensive definition of MCI in the exploration of personal experiences. Of the 17 participants 3 were single domain amnesic MCI, 11 were single domain non-amnesic, and 3 were multiple domain non-amnesic. The MMSE scores were in the range 27–30 with a mean of 29.1 ( $SD = 1.1$ ).

### Procedure

The interviewer (AIB) visited the participants in their homes with the exception of one participant who preferred to be interviewed at the memory clinic. Interviews lasted one to two hours and were recorded and transcribed. The interview started with the interviewer sharing information of the study before the first general question of why and how the participants first attended the memory clinic. As much information as possible was gathered from this central part of the interview in order to have participants to express their own understanding of the process from the stage of suspected dementia, through the years of re-visits at the memory clinic,

until the present day. After this open phase of the interview the participants were asked more specific questions concerning cognitive problems, health, well-being, stress, relationships, and perspective on the future.

### Instrument

A semi-structured interview guide was developed especially for this study with the intention to capture both subjective experiences of MCI and specific topics related to quality of life, social networks, coping strategies, and future expectations. All interviews were carried out by the same researcher (AIB).

The first part of the study focused on the time when the participant first came to the memory clinic and the cognitive and emotional experiences during the time that had past. This was explored using four broad and open-ended questions: 'Why did you attend the memory clinic?', 'Looking back, how was your life at the time for the first contact?', 'How is your life today?', and 'Have your life changed in any way?'

Next, participants were asked to describe their everyday life as reflected in the description of a 'normal day'. Follow-up questions addressed issues of hours of sleep, physical activities, leisure activities, social activities, and nutrition. The portrayal of a normal day was finally followed by questions of what makes a good day and what makes a bad day.

In a third step more specific questions were asked concerning experiences of stress and daily hassles, both at present and during the last seven years. When experiences of stress were reported, follow-up questions were asked about coping strategies and external resources in terms of social support.

### Data analysis

Data from the transcripts of the 17 interviews were analyzed using thematic analysis (Braun & Clarke, 2006). In contrast to the approaches within the theoretical tradition of analyzing qualitative data,

such as interpretative phenomenological analysis (IPA) (Smith & Osborn, 2003), the thematic analysis allows a more open and theoretically independent strategy that enables a rich and detailed account of data. In line with the guidelines from Braun and Clarke (2006), data were analyzed in different stages from the starting point when the interviews were transcribed to the identification of themes. First, to become acquainted with the text the transcripts were read repetitively and methodically. Then, initial codes were generated by tagging sentence by sentence after which each transcript was read again with the aim of identifying clusters of themes. The next step was to identify higher level clusters of key themes that would form sub-themes. When the described procedure had been conducted for each transcript, resulting in 17 sets of themes, the next step of the analysis was to organize the themes at the group-level and to construct group-level key themes. The themes were clustered and labeled with the most representative sub-themes. Finally, the structure of themes was used as a 'guide' in a re-reading and discussion of the transcripts together with two of the co-authors who had not taken part of the initial work with generating themes.

### Results

This study included 17 participants who were rated with MCI across four clinical investigation occasions over a time period of seven years. One individual was still working, another one had received an early retirement pension while the rest were all retirees ( $N=15$ ). Five individuals had contacted the memory clinic directly, six had been referred by their primary care physician and six had been referred by other specialist care.

As presented in Table 1, the analyses of the transcribed interviews of experiences of living with the MCI status resulted in the identification of four themes: *At that time, when I came to the Memory Clinic*; *Adjusting to reduced capacity*; *Worries about what is to come*; and *I have a good life*.

Table 1. Key themes and sub-themes.

Key themes	Contributing sub-themes
1. At that time – when I came to the memory clinic	1.1. My mother had Alzheimer's 1.2. It was a stressful period of my life 1.3. I was so relieved I didn't have dementia
2. Adjusting to reduced capacity	2.1. I have learned to avoid stress 2.2. Understanding from family 2.3. But what is normal?
3. Worries about what is to come	3.1. Experiences of dementia 3.2. Losing capabilities 3.3. The future is behind me
4. I have a good life	4.1 Freedom to do what I like 4.2. Right now everything is fine 4.3. Good relations matters 4.4. Activity



### *At that time – When I came to the memory clinic*

Participants had very specific perception about the time for their first contact with the memory clinic. It appeared that actually being enrolled to the memory clinic in combination with an extensive investigation at several consecutive visits contributed to solidify memories of the investigation including details from conversations with personnel and also the subjective perception of life at the time. The past was often described as utterly different from the present: in contrast to the satisfaction they experienced with the present life situation the time when they came to the memory clinic was a time characterized by stressful life events and stress at work often in combination with worries about memory problems.

- 1.1. *My mother had Alzheimer's.* Noteworthy, 11/17 participants mentioned a long and emotionally stressful period of caring for and finally losing their mother in a dementia disease and they all related the loss to the time of their first visit at the memory clinic. A: 'We didn't understand that she was sick. She did things that were crazy, swearing... Mum who never used to swear. And when she finally came to the memory clinic, even then those years were horrible... so I decided that I wanted to spare my own children and contacted the memory clinic'. Another participant had even more outspoken concerns about heritability: 'My mother and many of my uncles and aunts got the disease (AD) in early years. And when I started to lose things, forgot things, I decided to contact the clinic'.
- 1.2. *It was a stressful period of my life.* Memory problems related to high demands at work were related to the time they first came to the memory clinic. One participant described a long period of work-related stress: 'I had my own company... I worked a lot. Long days, evenings, and weekends. I worked so hard. And then I started to feel that I lost things, forgot words, things that I had to do. It was all confused. My doctor said I had a burnout depression. And my doctor told me to rest more'.
- 1.3. *I was so relieved I didn't have dementia.* Participants expressed being relieved after the first investigation at the memory clinic when told that the examination provided no evidence for Alzheimer's disease. 'Yes, I was really nervous before the first visit. And when I spoke to the doctor after the investigation, I was told that it was not Alzheimer I had. And it was so wonderful to hear that'.

### *Adjusting to reduced capacity*

Perceptions of being evaluated with MCI were expressed through the awareness of limitations of capacity. Even if none of the participants directly expressed that they had changed their lives in radical

ways, themes of adaptations to limited capacity appeared in the conversations. The mismatch between own cognitive capacity and the everyday demands of the environment was discussed and addressed in terms of an constantly ongoing internal adaptation process but questions were also raised about too high external demands.

- 2.1. *I have learned to avoid stress.* Most participants described experiences of burden of stress related to work, and they also made a contrast to their present situation and how they had learnt to cope with stress in constructive ways. Coping mostly involved learning to know and to live in accordance with one's own capabilities and how to avoid stressful situations. One participant described how stress was almost absent in her life after retirement, but that the thresholds for experiencing stress were lower: 'Yes, but you know, if we are having friends for dinner... I have to prepare days before. You know, I am a person that really wants everything to be nice, that it all runs smoothly. So I start with making a menu and do the shopping two days before'. Another participant describes another avoidant coping approach: 'Nowadays I know what to do and not to do. I don't put myself in those situations that stress me'.
- 2.2. *Understanding from family.* Being open with memory problems in relation to family and friends were essential in being able to handle memory problems. In living with MCI it seemed to be important to be understood and that the cognitive problems were recognized and respected in terms of adjusted demands from the social network. This was expressed in positive ways by one participant: 'You know, she is a nurse, so she is familiar with this condition. We both try to be understanding and to fix it in a good way. Making lists, reminding each other about important things'. Another described the absence of understanding of the partner: 'She doesn't really take any notice that I so easily get stressed and forget things. She complains about things I have forgotten during the days'.
- 2.3. *But what is normal?* Difficulties in determining when a memory problem is normal and when it is related to a decline in cognitive health were expressed. Participants made social and temporal comparisons to their present cognitive functioning. 'But my wife forgets things too. So you know, it is like it depends on who it is that forget things. When does it become a problem?' Another participant related the problems to normal cognitive aging: 'I am really not the same as I used to be. But on the other side, I am getting older, and I guess it is normal to forget names and such things... I mean at my age?' The perception of having changed in terms of strength and resilience is exemplified with one

participant who made a contrast of the present and past: 'What I nowadays get stressed about and upset for, this would have been just nothing earlier in my life, of course. You know, I took care of my sick mother, travelling across the whole country in my job, the marriage crisis on top of that, and all the stressful periods. Now I have to be careful'.

### *Worries about what is to come*

Although a few participants interpreted MCI as not being related to dementia, most expressed concerns about the future, to deteriorated memory functioning and also subsequent dementia.

- 3.1. *Experiences of dementia.* Most participants had experiences of dementia in their family and expressed concerns about heritability of Alzheimer's disease related to themselves and also to their children. The experiences were twofolded: both the distress related to a painful journey through the stages of dementia but also the worry whether one's own memory problems experienced in everyday life could be related to a progression to dementia. One participant had experiences of 'My mum demented, my grandmother likewise, and why I contacted the clinic was because I could feel the similarities with them. And I thought if one can detect it early in time there could be medications to prevent the condition. I don't know...but I felt scatterbrained. And I really think others find me scatterbrained'.
- 3.2. *Losing capabilities.* Participants expressed concern about not being able to continue performing activities in the future that were important in the present. 'It's this about the capacity, you know, it gets poorer as time passes. And what I worry most about is that my memory will get worse, that I have to give up dancing. That I will forget the steps'.
- 3.3. *The future is behind me.* On the question about their expectations of their future several participants expressed in different ways that they considered their lives coming to an end and that the future had little to offer them. The seemingly depressive statements are more complex than what it might seem like at first sight. One participant responded: 'The future? Oh, the future is behind me! (laughs) You know, I have had a great life, I have had a good job and kids, and... all that is behind me you know. I just hope I will have some good and healthy years now'.

### *I have a good life*

Despite the concerns related to memory problems and the future the actual here and now life situation was

often described in positive ways. Descriptions of being able to influence their lives as retirees or at work, planning and performing activities were central to well-being.

- 4.1. *Freedom to do what I like.* Participants expressed great satisfaction with the freedom of being retired and the possibility to influence and plan their days themselves. 'I go up and do things, fix with the flowers. In my night gown (laughs). And then I take my laptop and go to bed again to see TV-programmes that I missed last night. And then I have breakfast served, two eggs and two fruits. It's lovely to be a retiree'.
- 4.2. *Right now everything is fine.* Participants emphasized the strategy of taking one day at the time and in that way protect the present from future worries. One participant expressed this as a lifetime strategy of his: 'I have noticed that other people worry about what will happen tomorrow. But no, I don't. What happens happens. No point in worrying. I believe in faith'. Another participant also expressed trust in future despite of health and cognitive deteriorations: 'But on the other side, someday I have to quit dancing, getting older. And then I will find something else to do, you know. It will be all right'.
- 4.3. *Good relations matters.* The period of expected dementia and the worries about future deteriorations in cognitive health was handled with the support of close relations and family members. 'Without my husband I would never have managed this well. He is fantastic, cheers me up in his own evil way'. The importance of the quality of the social contact was also expressed: 'We do not see a lot of friends. Some people seem to have such large networks going to parties and always busy. But for us it is our close friends that matters'.
- 4.4. *Activity.* Participants were engaged both in social and physical activities and, despite the freedom of doing whatever they liked to, expressed the importance of structuring the days and weeks of their lives. 'As I use to say, I have never been as busy as now when I'm retired. Just have a look (pointing to a schedule on the fridge door) it's full. And the week before was just like that. I'm a member of two associations, and a choir, it takes a lot of time. Sometimes I think, my God how much, so many things I'm involved in. But it's not too much still. If I want to I can quit everything. As long as it gives me pleasure I continue'.

### **Discussion**

The participants in this study were heterogeneous concerning age, reasons for being enrolled to the first visit at the memory clinic, health status, and overall life

situation, but they all shared the experience of not converting to dementia over a time period of at least seven years.

The thematic analysis of their experiences of living with MCI revealed several common themes revolving around a stressful life situation and events related to the first visit at the memory clinic, various strategies to cope with compromised cognition, and worries about dementia and further cognitive decline.

Experiences of caring for own parents through the challenging progress of dementia until death in combination with work-related stress and worries related to the heredity of dementia was a common context for the perception and awareness of memory problems. Even if individuals with pronounced stress related problems were excluded from the study, there may still be a negative synergetic effect from the combination of specific negative life circumstances and stress. Future research needs to investigate multiple variables at the same time and investigate how these may interact. For clinical practice it is of specific importance to address the issue of worrying about heredity and to acknowledge and take into consideration the effects of personality and other individual differences.

Participants described prolonged periods of work-related or emotional stress in conjunction with their first visit at the memory clinic. Some individuals explicitly expressed an awareness of own limitations when exposed to stress to the mobilization of adaptive strategies to adjust everyday life demands to their own capabilities. Such adaptive strategies can be understood within the framework of aging theories of emotional regulation (Charles & Carstensen, 2010) and posttraumatic growth (Calhoun & Tedeschi, 1999); during the life course the individual is exposed to stressors that trigger the reflection and identification of person specific needs to optimize level of well-being. Being able to balance exposure and adaptation to own resources and preferences seems to be central for many individuals with MCI.

Although the participants were most disturbed about own observations of various memory problems, it seemed that the follow-ups at the memory clinic had a consoling effect on their distress which was highly related to the potential threat of subsequent dementia. Some participants explicitly said that they were nervous about the extensive investigations at the memory clinic the first times, but that they felt more relieved at present with results repeatedly showing that their cognitive health was not declining. They also expressed great gratitude to the personnel at the memory clinic and were moved when talking about their contact persons providing comfort in this respect.

There are limitations of this study related to selection: individuals who declined participation could represent a group of MCI-individuals differing from participants. To decline participation may be an expression of a qualitatively different experience of MCI. Also, a more age homogenous group could

probably result in more specific trends in the narratives because experiences of cognitive problems in 60-year olds is likely more challenging given the inappropriateness of explanations related to normal aging at these earlier ages. Despite the limitations due to potential selectivity, the aim of the study was to supplement the current main focus in MCI research with information about personal experiences of living with MCI. The results may hopefully guide further investigations with detailed comparisons between experiences of normal aging, stable MCI and early stage dementia in those who recently have converted from MCI.

A major aim in research on neurodegenerative diseases is to improve the specificity and sensitivity of diagnostic criteria and to differentiate between MCI individuals who will convert to dementia and those who are less likely to convert. An early identification of the MCI individuals who actually are in a preclinical dementia phase is crucial for treatments that may delay the progression to clinical dementia. Given the clinical uncertainty and the personal consequences associated with being identified with MCI it is warranted that we explore how a long-term MCI classification is perceived and actually handled at the individual level. This study generated findings that can be used both in research and in clinical practice, concerning the importance of addressing work-related and relational stress, worries about genetic risk and the identification of internal resources and different coping mechanisms (McIlvane et al., 2008). The study also revealed a need to address the role of external resources such as supportive social networks. The personally constructed narratives of living with MCI emphasize the significance of a life course model of cognitive health in which linkages are made between long-term stress and life events and transitions such as retirement and social network losses. Knowledge about an individual's perception and understanding of these changes may actually improve diagnostic accuracy. Despite the advances within the 'grey area,' as represented by the MCI classification, our understanding of cognitive health also needs to include potential psychosocial influences that can contribute to conversion or to stable MCI.

More efforts are needed to fully recognize the dynamics of multiple influences on cognitive functioning in the boundaries between normal and pathological cognitive aging that sometimes lead to largely preserved cognition also among individuals once found at risk for converting to dementia.

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