The process of decline in Advanced Activities of Daily Living: a qualitative exploratory study in Mild Cognitive Impairment

Patricia De Vriendt\textsuperscript{1, 3, 4}, Ellen Gorus\textsuperscript{1, 2, 4}, Elise Cornelis\textsuperscript{2}, Anja Velghe \textsuperscript{3, 4}, Mirko Petrovic \textsuperscript{3, 4}, Tony Mets \textsuperscript{1, 2, 4}

\textsuperscript{1}Frailty in Ageing (FRIA) research group and Gerontology department, Faculty of Medicine and Pharmacy, Vrije Universiteit Brussel, Laarbeeklaan 103, B-1090 Brussels, Belgium;
\textsuperscript{2}Department of Geriatrics, Universitair Ziekenhuis Brussel, Laarbeeklaan 101, B-1090 Brussels, Belgium;
\textsuperscript{3}Department of Geriatrics, Ghent University Hospital, De Pintelaan, 185, 9000 Ghent, Belgium;
\textsuperscript{4}Research in Gerontology and Geriatrics (REGG), Research Association between Faculty of Medicine and Pharmacy, Vrije Universiteit Brussel, Laarbeeklaan 103, B-1090 Brussels, Belgium, and Faculty of Medicine and Health Sciences, Ghent University, De Pintelaan, 185, 9000 Ghent, Belgium.

\textbf{Authors' titles}
Patricia De Vriendt (Ba Occupational Therapy, MrSc in Gerontology), Ellen Gorus (Prof. Dr., Ph. D., MrSc in Psychology, MrSc in Gerontology), Elise Cornelis (Ba Occupational Therapy, MrSc in Gerontology), Anja Velghe (MD), Mirko Petrovic (Prof. Dr., PhD, MD), Tony Mets (Prof. Dr., PhD, MD)

\textbf{Corresponding author}
Patricia De Vriendt, Laarbeeklaan, 103, B-1090 Brussels, Belgium, 00 32 479 654110 or 00 2 477 63 66 - fax 02 477 63 64, patricia.devriendt@uzbrussel.be
Abstract

Background:
The notion of 'minimal impairment in instrumental Activities of Daily Living (i-ADL)' is important in the diagnosis of Mild Cognitive Impairment (MCI), but is presently not adequately operationalized. ADL is stratified according to difficulty, complexity and also to vulnerability for early cognitive changes in a hierarchically threefold: basic (b)-ADL, i-ADL and advanced (a)-ADL. This study aims to gain a deeper understanding of the functional decline in the process of MCI.

Method:
In a qualitative design, 37 consecutive patients diagnosed with amnestic (a)-MCI and their proxies were interviewed at 2 geriatric day hospitals. The constant comparative analysis was used for the analysis.

Results:
The a-ADL-concept emerged as important in the diagnosis of MCI. All participants were engaged in a wide range of activities, which could be clustered according to the International Classification of Functioning, Disability and Health. Participants reported subtle difficulties in performance. A process of functional decline was identified in which adaptation and coping mechanisms interacted with the process of reduced skills, leading to an activity disruption and an insufficiency in functioning.

Conclusion:
This study asserts the inclusion of an evaluation of a-ADL in the assessment of older persons. When evaluating ADL at three levels (b-ADL, i-ADL and a-ADL) all the activities one can perform in daily living are covered.

Key words: functional impairment; early cognitive disorders; Alzheimer’s disease; Activities of Daily Living -evaluation; International Classification of Functioning, Disability and Health; ICF

Running title: Advanced ADL in Mild Cognitive Impairment
Introduction

Mild Cognitive Impairment (MCI) has become a major research topic in the field of dementia and associated disorders. Petersen et al. (Petersen, 2004; 2011) define MCI as a condition of objectifiable cognitive impairment that is of insufficient severity to warrant a diagnosis of early dementia or to cause substantial functional impairment, but that nevertheless results in subtle deficits, noted by the individual or a relative. The prevalence of MCI varies between studies, depending on the setting and the inclusion criteria. Population based studies in adults 60 years and older reported a prevalence ranging from 11% to 17% (Mariani et al., 2007).

MCI encompasses a heterogeneous group of four subtypes (Petersen, 2004) from which amnestic MCI (a-MCI) is considered to be important since it is seen as the preclinical phase of Alzheimer’s disease (AD). It is associated with an increased risk of rapid progression and even reduced survival (Petersen, 2004). Recently, the added value of biomarkers has been pointed out for the identification of prodromal Alzheimer disease (AD) although biomarkers only can be considered as supportive in the diagnostic framework (Dubois et al., 2010).

The identification of MCI patients remains difficult and could benefit from refinement of clinical measurement tools. Presently, the diagnosis is mainly based upon clinical judgment and a multidisciplinary approach. The criterion regarding the Activities of Daily Living (ADL) which states that ‘basic ADL (b-ADL) are preserved and a minimal impairment in instrumental ADL (i-ADL) is allowed (Winblad et al., 2004) is pivotal in the distinction between normal cognitive ageing, MCI and early AD. The notion of ‘minimal impairment’ determines the difference between MCI and normal ageing or AD, but presently neither age-specific norms for levels of functioning nor normal rates of age-related functional decline are available. Moreover, commonly used instruments like the Lawton scale (Lawton and Brody, 1969) are not sensitive enough to detect mild limitations in functioning. Refinement of existing and inclusion of contemporary items, taking into consideration an increased use of technology in housekeeping and daily living, is needed (Nygard, 2003; Sanchez-Benavides et al., 2009). Another difficulty is that most ADL-assessment tools do not distinguish between motor and processing skills (Nygard, 2003), while only functional loss due to cognitive deficits has to be considered for the diagnosis of MCI.

The question remains which ADL domains may be impaired and to what extent, since controversy exists whether functional limitations are part of the MCI complex or announce already a conversion towards AD (Farias et al., 2008; Farias et al., 2006; Jefferson et al., 2008; Mariani et al., 2007; Perneczky et al., 2006; Petersen, 2011). Several typologies are available to describe daily activities. What the distinction between
b-ADL, i-ADL and advanced ADL (a-ADL), as proposed by Reuben et al. (Reuben et al., 1990), ADL is stratified according to difficulty and complexity. The b-ADL describe the activities that meet basic physiological and self maintenance needs. These are relatively uniform across people and cultures. The i-ADL include more complex activities, essential to maintain independent living. The a-ADL cover those activities that are volitional, influenced by cultural and motivational factors, expressing a personal engagement in satisfying activities which are beyond what is needed to be independent (Reuben et al., 1990).

Functioning is complex and requires cognitive, motor, and psychological skills, as well as the appropriate environmental conditions (WHO, 2001). The more complex the activities are, the more complex also the cognitive functions involved. The i-ADL require a greater complexity of cognitive organization than b-ADL and are assumed to be more vulnerable for early cognitive changes (Njegovan et al., 2001; Peres et al., 2006; Tuokko et al., 2005; Yeh et al., 2011). Therefore, the subtle cognitive changes in MCI might first cause problems in a-ADL, before they appear in i-ADL assessment (Pedrosa et al., 2010).

For this study we hypothesized that patients with MCI show already subtle functional deficits in a-ADL. Moreover, we explored which a-ADL were impaired and to what extent. An additional objective of this study was to gain a deeper understanding of the functional decline in the process of MCI.

Participants and Methods

Instruments and data collection

In contrast to earlier published quantitative studies (Farias et al., 2006; Geda et al., 2011; Pedrosa et al., 2010) a qualitative inductive design was chosen in order to explore the individual’s point of view and his unique lived experience. The topics of the individual, semi structured in depth interviews covered the participant's experiences with regard to his or her daily activities and changes in performance occurring over time. The subjective cognitive complaints were taken as a start for the interview and were followed by the simple question ‘can you describe a typical day’. Then interview questions focused on the a-ADL performed by the subject and experienced problems. By using eliciting probes, the interviewees were encouraged to elaborate and deepen their answers. Each interview lasted approximately one hour. The collected data consisted of ‘oral narratives of personal experiences’, which is, according to Lindseth and Norberg (Lindseth and Norberg, 2004) ‘an appropriate method for disclosing the meaning of the phenomenon under investigation’. Interviews were taped and transcribed verbatim.
Participants and sampling strategy

Using homogeneous purposive sampling, patients were recruited from the geriatric day hospitals of the Universitair Ziekenhuis Brussel and the Ghent University Hospital. We included consecutive patients, newly diagnosed with a-MCI, using the criteria described by Winblad et al. (Winblad et al., 2004). Only patients with a-MCI were included, since this subtype has the highest risk to evolve towards AD. Exclusion criteria were dementia, Mini Mental State Examination (MMSE) (Folstein et al., 1975) score below 24/30, any other mental disease, and any condition that precluded the participants from being interviewed.

A multidisciplinary evaluation was performed, encompassing MMSE (Folstein et al., 1975), Cambridge Examination for mental disorders of the elderly, cognitive part (CamCog) (Roth et al., 1986), educational level (expressed in years), Geriatric Depression Scale (GDS) (Yesavage et al., 1982), b-ADL, according to a modified Katz scale (scores calculated as a percentage, higher scores representing higher dependence) (Katz et al., 1963), i-ADL, according to a modified gender specific Lawton Scale (Lawton and Brody, 1969) (for women a 8 item version (food preparation, housekeeping, laundry, ability to use telephone, shopping, transportation, handling medication and finances); for men a 6 item version (ability to use telephone, shopping, transportation, handling medication, handling finances an handyman work), scores calculated as a percentage, higher scores representing higher dependence), physical examination, the Charlson Comorbidity Index (Charlson et al., 1987), extensive laboratory testing, and imaging of the brain (CT scan or MRI).

As additional validation we applied a triangulation approach within the data collection by interviewing as many proxies as possible in order to gather different perspectives of the investigated phenomenon. Subjects were included until saturation of the data was achieved. Data saturation occurs when no new information is obtained during analysis. At the Universitair Ziekenhuis Brussel, 29 patients and 20 proxies (9 spouses and 11 children) were included. Interviewing the last of these 49 subjects and analyzing the narratives, gave no new information regarding the research questions. Based on the same sampling strategy 8 new patients and 2 proxies (2 children) were sampled in the Ghent University Hospital, in order to validate the ongoing analysis and to ascertain that saturation has occurred. This cohort did not reveal any new information.

Data processing and analysis

In the analysis we used an open-minded approach, looking for relevant phenomena. For this purpose we constantly compared data gained in the different interviews (Bogdan, 2003).
A first analysis, line by line, resulted in a description of the activities performed by the participants. These activities were clustered according to the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), using the linking rules (Cieza et al., 2005). Subsequently, the data were read several times in order to understand their meaning, the so called naïve understanding (Lindseth and Norberg, 2004). These preliminary results were presented to a panel consisting of physicians, psychologists, gerontologists and occupational therapists, specialized in geriatrics. After peer review, a structural analysis of the data was conducted seeking to identify meaningful themes. Finally, in a more in depth analysis themes were brought in relation with each other and reflected on in relation with the research questions, resulting in a comprehensive understanding of the process of functional decline in MCI (see figure 1).

The study was approved by the Ethical Committee’s of both hospitals. The participants gave their informed consent. All data were collected in concordance with the Declaration of Helsinki.

**Results**

We included 37 participants (11 men, 26 women; mean age 77,3 year; SD 5,6; range 66- 87 year) all of them meeting the criteria of a-MCI and 22 proxies. Table 1 shows the characteristics of the participants. All patients were found to be very capable of sharing experiences about their daily life.

**Naïve understanding**

*Description of the activities performed by the participants*

Although the number of activities could vary, all the participants were engaged in a range of meaningful activities. ‘What’, ‘how’, and ‘how much’ differed among participants and was influenced by personal factors (such as personal occupational life history, cultural context, individual capacities and limitations, and environmental barriers or facilitators). The activities, reported by the participants were clustered based on the ICF. We identified a variety of clusters and relevant ICF-codes for each activity. For each participant the reported activities covered multiple clusters (see table 2 for a definition of each cluster and a complete list of these activities).

*Description of the functional problems as experienced by the participants*

The participants did not report any functional problem due to cognitive problems. However, when asked to describe a ‘typical’ day, they all reported subtle difficulties in,
for example, their hobby and leisure activities. Table 2 provides a typical example of the reported problems for each cluster.

The process of change was characterized by a slow and fluctuating onset. All participants mentioned the unnoticed beginning of the performance problems and the unpredictability of the impairment. Even at the time they came to the hospital, seeking for help and answers, the performance problems were not continuously apparent. The participants acknowledged that their number of activities was reduced, possible because it required more energy to perform activities. They discussed in this context the process of giving up activities. Generally, the process of quitting an activity evolved slowly from a temporary over a gradual towards a complete stop. Sometimes they discontinued an activity, intending to start again later on or 'when they got better'. In the latter case, they really expected that their situation would improve again. Because the activities demanded more energy and more attention, they kept postponing them thereby increasing the threshold to take up the activity. Some participants reported a complete cessation of their favorite activities due to the problems experienced while performing. Giving up was most often due to a combination of factors: feeling one’s own mental limitations combined with e.g. the loss of a friend to enjoy the activity with, the occurrence of a medical problem or an event like moving to an apartment and leaving familiar surroundings.

**Structural analysis**

Whereas the naïve understanding showed the various impaired activities, the structural analysis revealed the underlying deficient capacities and the associated consequences, regardless of the activity involved. The phenomena that appeared to have a major impact on the occupational performance of the participants, are incorporated in figure 1 as ‘diminished performance skills’ and ‘reduced adaptation and coping mechanisms’. We observed a strong relationship between these factors.

**Diminished performance skills**

Participants were less able to monitor the different steps of a task, which, consequently, was not performed correctly, leading to less satisfaction, thereby initiating a vicious circle. In addition, the participants reported a lack of initiative and perseverance. Making plans, starting things and keeping them going, was found to be difficult. The participants mentioned ‘black outs’ or ‘short circuits’. From their point of view, the difficulties occurred occasionally and not continuously. It felt like sudden and unexpected moments of errors, taking them by surprise. Afterwards, everything went back to normal. The cognitive problems seemed to have a negative impact on the participants’ creativity, leading to less creativity. Often mild mistakes occurred,
characterized by carelessness or inaccuracy and generally not harmful. The participants acted slower than they used to and double tasks became a major problem. They reported problems with sequencing (performing the components of a task in the right sequence). It could happen that a necessary step in the activity was forgotten, affecting the final result. Many participants did not make full use of their electronic devices. They said that it was too difficult to learn all those new things. Many participants seemed to suffer from reduced attention. They reported problems to stay focused on a task or going back to the task after distraction. The mild cognitive problems seemed to affect in particular the functional orchestration, as the participants reported problems with time management and organization of their daily occupations. They were not able to organize their daily living and to make their own daily schedule and mentioned problems with the subjective experience of the duration and passage of time. Some participants reported disturbances in their normal routine activity patterns and consequently living in a chaotic way.

**Insufficient adaptation and coping mechanisms**

When trying to cope with their functional problems, participants mentioned having difficulties to adapt to a new situation or a diminished flexibility to react to unexpected events. In order to be able to continue their preferred activities, participants used several adaptation strategies. Some performed the activities in a different, easier way, using compensation. Some participants used selection and continued only those activities they loved most and abandoned others. Some participants reported a need for external aid in performing activities. This external aid could be the assistance of another person, or an assistive device, such as a recipe, a manual, a (self) written note. On the other hand, they also reported difficulties with the ‘usual’ external aids available such as to follow a manual for electronic equipment. Decreased or increased self control or the use of self-deceiving strategies were additional mechanisms reported by the participants.

Participants described a process of mutual influence between the diminished performance skills and reduced adaptation and coping mechanisms. Some of the participants did not experience problems with executing an activity because they could rely on strong adaptation mechanisms, others did not succeed to overcome minor daily problems.

**Comprehensive understanding**
The interaction of diminished performance skills with reduced adaptation and coping mechanisms, reinforcing each other, resulted in a process leading to emotional and functional consequences (see figure 1).

**Emotional and functional consequences**

If the diminished skills on the one hand and insufficient adaptation and coping strategies on the other hand enforced each other, the participants were caught in a vicious circle, since the mechanisms described above led to a variety of emotional and functional consequences, with primarily feelings of **general discontent**. The participants admitted that they felt being less accurate in what they were doing and that it became difficult to be meticulous in their activities. The results of the activity were not sufficiently satisfying anymore, provoking a feeling of general discontent. Although this caused no emotional problems for some of them, others felt overwhelmed by **life stress**. As activities took more energy and the participants experienced problems in performing them, they reported to experience less pleasure. The feeling of making mistakes led to uncertainty about themselves and to doubt about their performance. This process resulted in a **decreased satisfaction with functioning**.

**Experience of activity disruption**

The diminished skills on the one hand and the reduced adaptation and coping strategies on the other hand, when resulting in negative emotional and functional consequences, could lead to an ‘**activity disruption**’. This was experienced as a transient or temporary condition of not being capable to perform an activity as desired. In figure 1 it is represented as an intermediate condition between the negative emotional and functional consequences and the more permanent experience of insufficiency in functioning.

**Experiences of insufficient functioning**

If the disruption persisted over time and resulted in discontinuity of daily life and occurred in different activities, it might lead to an insufficiency in functioning. Some participants were not able to adjust and their activities did not match their skills. One of the participants gave an explicit description of the process. She had recently moved into a new house and reported problems functioning in this new environment. She could not act as well as she used to. It started with little things, as not finding her belongings, nothing really problematic.

...‘I need to think and keep my attention to what I am doing, and I am tired of thinking! In earlier days, I managed to do thousand things at the same time’...

Subtle problems appeared.
...‘To estimate the needed ingredients for cooking comes difficult, I have too much food in my fridge these days’...

She liked to cook special dishes but at this moment she wasn’t able to do so without a recipe. Her daughter had to write it down for her.

...‘I know I have difficulties to prepare special dishes, particularly dishes from long ago. I have to be in control of myself, I can not permit myself to forget thinking while I act... I received a coffee machine for my birthday and I like it a lot. It is a very easy way to make coffee since I am alone. I use it every day, for my morning coffee and in the afternoon. And what happened last day? I forgot to put the coffee pad in the machine!’...

At the end she expressed her feelings of insufficiency.

...‘I have problems with organizing my daily life. I am not able anymore to structure the day. I am sad, frustrated.’...

On the other hand, activity disruption does not necessarily lead to an insufficient functioning. Other participants felt they were in balance since they were able to organize and participate in activities congruent with their capacities, desires and values and they felt able to adjust or respond to changing circumstances.

...‘I feel complete and I am satisfied with my activities. I know objectively, I am doing less than before, and not that good anymore, but it feels OK. It doesn’t feel like I am performing less or poorer ... I like to do things, regularly, I need that. I want to have something to do every day and I want to do it well’ ...

Discussion

Currently, the distinction between cognitive healthy ageing, MCI and early AD remains difficult. Particularly with regard to the ADL-criterion there is still uncertainty on how much activities have to be impaired and in which domains the impairment should be observed. The present qualitative study was conducted to explore the decline in ADL performance in patients with MCI. We hypothesized that people with MCI are facing problems in a-ADL and we investigated which activities were impaired and to what extent.

Many quantitative studies show that persons with MCI have more deficits in ADL than cognitively normal people although these deficits are subtle (Farias et al., 2006; Jefferson et al., 2008; Mariani et al., 2007; Perneczky et al., 2006; Yeh et al., 2011) which is in line with our results. These studies have documented problems with shopping, self administration of drugs, handling financial affairs, checking ones bank account, housekeeping, finding things at home, keeping appointments, remembering things from a conversation or from television, organizing travel or leisure. The results of our study show that people diagnosed with MCI don not have performance problems in b-ADL and
i-ADL due to cognitive problems, as could be expected according to the currently used definition (Winblad et al., 2004). However, all participants reported subtle problems in performance when it concerned the more complex ADL such as leisure, self development, or (semi) professional work. Geda et al. (Geda et al., 2011) have reported a significant difference between cognitively normal people and people with MCI concerning the frequency of performing cognitively demanding activities, such as reading books, playing games, craft activities, etc. Based on the analysis of our narrative data we succeeded to document the mild diminished performance skills observable in MCI: people with MCI could still carry out cognitive demanding activities, albeit with mild but disturbing performance problems.

In the present study, we describe these advanced activities in detail. Earlier studies do not discuss all a-ADL items in depth. Moreover, there is no uniformity in rapportation of the items and most of these studies do not bring structure in the deficits. Some studies focused on social activities (James et al., 2011) like going to restaurants, doing voluntary work, etc. Others focused on cognitive activities (Geda et al., 2011) or on complex ADL (Pedrosa et al., 2010; Perneckzky et al., 2006), which included also the common i-ADL besides activities such as the ability to maintain a job, play games etc. In our study, we tried to operationalize the concept of a-ADL as launched by Rueben et al. (Reuben et al., 1990) which clearly distinguishes between the various domains of ADL. Moreover, we have extensively described the various activities, providing also a systematic clustering. We succeeded in classifying all the a-ADL which were mentioned by our participants according to the ICF terminology. The use of the ICF classification allows to structure these heterogeneous a-ADL functions and thus facilitate the communication between health care workers, as recently recommended (Freedman, 2009; Jette, 2009).

Although b-ADL and i-ADL are commonly assessed, the evaluation of a-ADL is currently not systematically included in clinical practice and the diagnostic criteria for cognitive disorders mainly focus on i-ADL (Farias et al., 2008; Farias et al., 2006; Giovannetti et al., 2008; Jefferson et al., 2008; Nygard, 2003; Peres et al., 2006; Petersen, 2004; Winblad et al., 2004). When evaluating ADL at three levels, b-ADL, i-ADL and a-ADL, all the activities one can perform in daily living are covered. The results of our study assert the need to include an evaluation of the a-ADL in the diagnostic approach of older patients, thus extending the scope of a comprehensive geriatric assessment.

A difficulty in the assessment of older participants is that an observed functional decline can be caused by the interplay of several factors. Besides the cognitive and emotional problems as reported here, physical limitations and environmental barriers can
hamper performance (WHO, 2001). In this study a major challenge was to direct the focus of the interviews to the cognitive problems and the associated functional consequences.

The a-ADL clusters that we describe might be used in new assessment tools. Since these activities are influenced by cultural and motivational factors, and present a strong individual variation (Reuben et al., 1990), it will be a challenge to assess them in a standardized way. Future measurement tools have to take into account the personal preferences of people in order to capture limitations in the meaningful activities of the individual.

Through further analysis, a sequential and cyclic process of functional decline emerged. This is summarized in figure 1. In the light of what most people would consider a meaningful and active life, several problems with performance occurring in MCI could be distinguished. Diminished skills emerged, regardless of the activity involved. We noticed that particularly adaptation and coping mechanisms interacted with the process of reduced skills. In dementia, it has already been described that the cognitive disorder particularly undermines the coping resources of the individual (Kitwood, 1993; Preston et al., 2007). Based on the narratives of the participants, we assume that this process already starts in MCI. A study focusing on how people with dementia cope with ADL problems (Nygard and Ohman, 2002) revealed that they mainly use intuitive coping strategies such as trial and error, verbalizing or seeking external help. Besides these strategies, we also observed in our studies other ones such as avoidance (minimizing the impact of the memory problems), emotional regulation (Ferguson and Cox, 1997) and problem focused strategies (Lazarus and Folkman, 1984).

The narratives of the participants showed that the cyclic process of adaptation and coping mechanisms interacting with the process of reduced skills could lead to a variety of emotional and functional consequences. It is known that the development of coping and adaptation strategies is crucial in order to optimize wellbeing (Robinson et al., 2005) and successful ageing (Baltes and Baltes, 1990). For some participants who failed to adapt to the changing situation, it led to life stress. The continuing presence of negative elements, enforcing each other led to activity disruption. If this disruption persisted over time and occurred in different activities, an insufficiency in functioning was observed. This may suggest that the absence of adequate coping strategies in this early stage of cognitive decline contributes to the process of functional decline. Although the participants were not always fully aware of this insufficient functioning, it was apparently at this point that they started to seek professional help for their cognitive complaints.
In conclusion, we have tried to further elaborated the concept of a-ADL. We have described a comprehensive model of functional decline, grounded in the bio-psycho-social framework of the ICF, which brings impairment in relation to personal and contextual factors, trying to capture the complex interplay of all elements of advanced functioning. We propose that the standard approach of evaluating b-ADL and i-ADL, should be completed by a-ADL assessment when confronted with early signs of cognitive deterioration.

Conflict of interest declaration
None

Description of authors’ roles
All authors have agreed to be listed as authors. They all have actively participated in the collaborative work. P. De Vriendt, E. Gorus, M. Petrovic and T. Mets designed the study; P. De Vriendt collected data, supervised the collection of the other researchers, analyzed the data and wrote the paper. E. Cornelis collected data, analyzed them and assisted with the writing of the paper. E. Gorus, A. Velghe, M. Petrovic and T. Mets participated in the analysis and interpretation of the data and in the writing of the paper. All authors have seen the final version and approved it.

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References


doi:10.1016/S1474-4422(10)70223-4


doi:10.1037/0894-4105.22.4.531


doi:10.1097/01.wad.0000213849.51495.d9


doi:10.1176/appi.neuropsych.23.2.149

doi:10.1093/gerona/glq231

doi:10.1097/JGP.0b013e318162f197


doi:10.1111/j.1471-6712.2004.00258.x


doi:10.1212/01.wnl.0000228228.70065.f1

doi:10.1093/ageing/afj054


doi:10.1056/NEJMcp0910237

doi:10.1080/13607860600844572


doi:10.1080/13607860500114555


doi:10.1159/000228259
doi:10.1080/13554790490896802


doi:10.1111/j.1365-2796.2004.01380.x

doi:10.1159/000326910


**Figures/tables legends**

Table 1: Characteristics of the participants (n=37)

<table>
<thead>
<tr>
<th>MMSE: Mini Mental State Examination; CamCog: Cambridge Examination for mental disorders of the elderly, cognitive part; b-ADL: basic activities of daily living; i-ADL: instrumental activities of daily living; GDS: geriatric depression scale; SD: standard deviation.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Number or %, mean ± SD (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men/women</td>
</tr>
<tr>
<td>11/26</td>
</tr>
<tr>
<td>Age (years)</td>
</tr>
<tr>
<td>77.3 ±5.6 (66-87)</td>
</tr>
<tr>
<td>Living independently</td>
</tr>
<tr>
<td>37</td>
</tr>
<tr>
<td>Education (years)</td>
</tr>
<tr>
<td>11.7 ±1.6 (9-16)</td>
</tr>
</tbody>
</table>

Table 2: Clusters of activities based on the International Classification of Functioning, Disability and Health (ICF) (ICF-codes) and description; activities as reported and an example of a reported problem

Figure 1: The process of functional decline in MCI
<table>
<thead>
<tr>
<th>Charlson Comorbidity Index</th>
<th>4.9 ±1.9 (2-10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MMSE-score</td>
<td>27.6 ±1.6 (24-30)</td>
</tr>
<tr>
<td>CamCog-score</td>
<td>90.1 ±6.6 (78-101)</td>
</tr>
<tr>
<td>b-ADL</td>
<td>27.37 ± 5.41 (25-50)</td>
</tr>
<tr>
<td>i-ADL</td>
<td>44.7 ± 14.68 (33-83)</td>
</tr>
<tr>
<td>Risk for depression (GDS)</td>
<td>5</td>
</tr>
</tbody>
</table>

MMSE: Mini Mental State Examination; CamCog: Cambridge Examination for mental disorders of the elderly, cognitive part; b-ADL: basic activities of daily living according to Katz scale with higher % representing higher dependency; i-ADL: instrumental activities of daily living according to Lawton scale with higher % representing higher dependency; GDS: geriatric depression scale; SD: standard deviation.
Table 2: Clusters of activities based on the International Classification of Functioning, Disability and Health (ICF) (ICF-codes) and description; activities as reported and an example of a reported problem

<table>
<thead>
<tr>
<th>Cluster of activities</th>
<th>Description</th>
<th>Activities as reported</th>
<th>Example of experienced problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special self-care activities ICF d570</td>
<td>Activities to look after one's health by being aware of needs, prevent illness or avoid risks</td>
<td>Take care of stoma / fistula / colostomy, To perform own kidney dialysis, To control, monitor glycaemia, To use assistive devices (e.g. hearing aid)</td>
<td>Becoming less careful while performing kidney dialysis at home</td>
</tr>
<tr>
<td>Sophisticated kitchen activities ICF d6301</td>
<td>‘Advanced’ cooking, complex meals with a large number of ingredients, using complex methods of preparing or making dinner with several courses; baking bread, cakes</td>
<td>To freeze vegetables, To use coffee machine, To bake cakes and cookies, To bake bread and pastry, To cook special dishes, To use recipes from a cookery book, To cook for friends, To make family dinners on special occasions, To organize a (birthday) party, To organize coffee tables for the members of a club, To cook special dinners for the local government</td>
<td>Not being able anymore to prepare several courses simultaneously and having them on the table at the right time</td>
</tr>
<tr>
<td>Household appliances and daily technology ICF d6403</td>
<td>The use of dishwashers, micro wave ovens, washing machines, dryers, digital television, DVD and other electronic equipment</td>
<td>To use: (Digital) TV, Radio, Tape recorder, DVD, Dish washer, Dryer, Laundry machine, Air-conditioning, Alarm, To work with the computer: - Use specific programs, - To play computer games, - Mailing, - To invest capital with PC, To use manuals for electronic equipment</td>
<td>Not being able to manage digital television and – after trial and error – not succeeding to restart the program.</td>
</tr>
<tr>
<td>Gardening ICF d6505</td>
<td>Cultivating vegetables or rare plants</td>
<td>To cultivate special kind of vegetables, rare vegetables, To cultivate special or rare plants in pots</td>
<td>Becoming less careful with trimming the hedges, with as result that the hedge did not grow anymore the year after</td>
</tr>
<tr>
<td>Cognitive stimulating activities or intellectual</td>
<td>Playing cards, scrabble, solving cross words, reading books, professional literature, books and magazines in other languages; working with PC,</td>
<td>To take part in an ‘investment game’ through PC, To play social games (e.g. cards), To play games on the PC, To learn new things</td>
<td>Not being able to read literary masterpieces anymore because of the confusion of all the characters</td>
</tr>
<tr>
<td>Activities</td>
<td>Playing Computer Games</td>
<td>To Make</td>
<td>To Read Magazines</td>
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<tr>
<td>ICF d166 &amp; d9200</td>
<td>Playing computer games</td>
<td>Cross words</td>
<td>Word seekers</td>
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<td></td>
<td></td>
<td>To read magazines</td>
<td>In other languages</td>
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<td></td>
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<td>Geographic or historic magazines</td>
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<td></td>
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<td>To read fiction books</td>
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<td>To read non-fiction books</td>
<td>Psychological, philosophy, religion</td>
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<td>Professional literature</td>
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<tr>
<td>Craftwork and arts</td>
<td>Knitting, sewing, repairing clothes, like reattaching buttons and fasteners; painting, sculpting</td>
<td>To sew</td>
<td>To tailor clothes</td>
</tr>
<tr>
<td>ICF 6500 &amp; d9203</td>
<td></td>
<td>To repair clothes</td>
<td>To knit (sweaters, pull over's)</td>
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<td></td>
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<td>When tailoring new pants, making the same leg twice</td>
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<tr>
<td>Complex economic activities or transactions ICF d865</td>
<td>The use of bank cards, ‘money out the wall’, PC-banking, trading in commodities</td>
<td>To take money out the wall</td>
<td>To transact financial papers (savings certificates) or trade in commodities</td>
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<td>To invest</td>
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<td>Using an insurance card instead of a credit card while trying to pay electronically and thereupon not remembering the code anymore</td>
</tr>
<tr>
<td>To communicate by using devices or techniques ICF d360</td>
<td>Use of cell phone, e-mail</td>
<td>To use cell phone</td>
<td>To use email</td>
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<td>To write letters</td>
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<td>Blocking the cell phone completely, by striking the wrong key and not being able to unlock it</td>
</tr>
<tr>
<td>Sports ICF d9201</td>
<td>Informal or organized sports: group activities and sporting on your own (e.g. fishing)</td>
<td>To do gymnastics (in group)</td>
<td>To swim (in group)</td>
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<td>To do aqua gym</td>
<td>To do a home trainer</td>
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<td></td>
<td>To use a home trainer</td>
<td>To sail</td>
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<td>To fish</td>
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<td>To dive</td>
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<td>To do Yoga</td>
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<td>To play golf</td>
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<td>To drive a bike</td>
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<td>To play billiards or snooker</td>
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<td>Problems with sailing because the timing of handling the sails (rising and hoisting) isn’t right anymore</td>
</tr>
<tr>
<td>Transportation by motorized vehicles ICF d475</td>
<td>Driving a car, motorcycle</td>
<td>To drive a motorized vehicle</td>
<td>Having problems with driving the car in an unfamiliar area, because of the inability of combining driving, talking with passenger and orientating in the environment</td>
</tr>
</tbody>
</table>
| Leisure activities, socializing | Activity only for amusement or relaxation, with a social component (e.g. go out for dinner) | To go out for dinner, lunch  
To go on a day trip with the club  
To visit family | Minimizing the participation in family visits because these are to demanding in daily life structure |
|--------------------------------|-------------------------------------------------------------------------------------------------|-------------------------------------------------------------|---------------------------------------------------------------------|
| Self development/self realization/self educational activities | Formal or informal learning: attending a course, going to lectures, or visiting exhibitions, musical performances | To attend a course (e.g. PC course)  
To attend a lecture  
To attend  
- art exhibition  
- theatre  
- opera  
- musical  
- concert  
- film  
- lecture  
To buy art | Experiencing problems with learning new terms and working with new materials like the PC |
| To go on a holiday | Holiday in own cottage or participating in group trips | To own cottage  
To rent a cottage  
To travel  
To go on city trips | Problems with organizing holiday household, because of the complexity of having 2 households at the same time |
| Caring for or assisting others | Caring for household members, often by assisting for with b-ADL or i-ADL; taking care of pets | To take care of the partner (e.g. preparing medication)  
To help children with things in the house  
To take care of grand children  
To cook for family  
To take care of the dog (of the daughter), own pets (dog, bird, cat, …) | Difficulties in caring for the grandchildren because the games they are playing are to difficult to understand |
| Caring for household objects | Painting, wallpapering rooms, fixing furniture, small plumbing | To do difficult jobs  
To do carpentry  
To work on electricity  
To paint the walls  
To paper walls  
To help the children to build their house | While papering the wall, not being able anymore to fit the pattern |
| Semi professional work | Work as a volunteer, non-remunerative employment, semi professional work: social, administrative, accountancy jobs | To visit older people in a residential home  
To work in a residential home  
To work as a nurse in ‘Child and family’ service  
To work as administrator in own apartment building or as delegate for the habitants  
To do accountancy/bookkeeping in the business of the son | Still being able to review the papers of others, but writing a book became too difficult |
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<td>To work in Social Welfare: to organize the mailing in the home</td>
<td></td>
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<tr>
<td>To maintain a fishing pool</td>
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<tr>
<td>To trim dogs</td>
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<tr>
<td>To have some clients for insurances (from his professional period)</td>
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<tr>
<td>To work in the library: to register new books</td>
<td></td>
</tr>
<tr>
<td>To manage the rent of apartments</td>
<td></td>
</tr>
<tr>
<td>To work in the family business, doing the office, telephones, shops, making invoices, etc.</td>
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</tr>
<tr>
<td>To work for the priest and church community</td>
<td></td>
</tr>
<tr>
<td>To deliver the club magazine to the members of the club</td>
<td></td>
</tr>
<tr>
<td>To be responsible for the local community of the club (visit ill persons, membership, collecting fees, …)</td>
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<tr>
<td>To organize activities such as art exhibition, choir, card clubs…</td>
<td></td>
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<tr>
<td>To help when the local government organizes dinners</td>
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**Engagement in organized social life**

- ICF d910

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**Problems to engage actively in a meeting**

- It takes too long to think about what to say and then the subject of the meeting already changed into another item
Figure 1: the process of functional decline in MCI

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<tr>
<th>Method of analysis</th>
<th>Naive understanding</th>
<th>Structural analysis</th>
<th>Comprehensive understanding</th>
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Results

**a-ADL and process of change in functioning as experienced**

- Diminished performance skills
  - Less monitoring
  - Lack of initiative
  - Black outs and short circuits
  - Less creativity
  - Carelessness and inaccuracy
  - Slower
  - Problems with sequencing
  - Problems with double tasks
  - Not utilizing full range of applications
  - Reduced attention
  - Problems with time use and daily organization
  - Disturbance in activity patterns

- Reduced adaptation and coping mechanisms
  - Need for external aid
  - Compensation strategies
  - Self deceiving
  - Decreased or increased self control

Emotional and functional consequences

- General discontent
- Life stress
- Decreased functional satisfaction

Experiences of activity disruption

Experiences of insufficiency in functioning *

* When activity disruption is experienced repeatedly and in several activities