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

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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)* ENREF_7*'* 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. Whit the distinction between

b-ADL, i-ADL and advanced ADL (a-ADL), as proposed by Reuben et al. (Reuben *et al.*, 1990), _ENREF_22 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 _ENREF_12_ENREF_1_ENREF_13 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) ENREF 22. 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). Subesequently, 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.

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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. _ENREF_28For 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.

<u>Comprehensive understanding</u>

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 descrive 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; Perneczky *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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Figures/tables legends

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

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.

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 1: Characteristics of the participants (n=37)

	Number or %, mean ± SD (range)
Men/women	11/26
Age (years)	77.3 ±5.6 (66-87)
Living independently	37
Education (years)	11.7 ±1.6 (9-16)

Charlson Comorbidity Index	4.9 ±1.9 (2- 10)
MMSE-score	27.6 ±1.6 (24-30)
CamCog-score	90.1 ±6.6 (78-101)
b-ADL	27.37 ± 5.41 (25-50)
i-ADL	44.7 ± 14.68 (33-83)
Risk for depression (GDS)	5

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

Cluster of activities	**Description**	**Activities as reported**	**Example of experienced problem**
Special self-care activities ICF d570	Activities to look after one's health by being aware of needs, prevent illness or avoid risks	Take care of stoma / fistula / colostomy To perform own kidney dialysis To control, monitor glycaemia To use assistive devices (e.g. *hearing aid)*	Becoming less careful while performing kidney dialysis at home
Sophisticated kitchen activities ICF d6301	'Advanced' cooking, complex meals with a large number of ingredients, using complex methods of preparing or making dinner with several courses; baking bread, cakes	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	Not being able anymore to prepare several courses simultaneously and having them on the table at the right time
Household appliances and daily technology ICF d6403	The use of dishwashers, micro wave ovens, washing machines, dryers, digital television, DVD and other electronic equipment	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	Not being able to manage digital television and – after trial and error – not succeeding to restart the program.
Gardening ICF d6505	Cultivating vegetables or rare plants	To cultivate special kind of vegetables, rare vegetables To cultivate special or rare plants in pots	Becoming less careful with trimming the hedges, with as result that the hedge did not grow anymore the year after
Cognitive stimulating activities or intellectual	Playing cards, scrabble , solving cross words, reading books professional literature, books and magazines in other languages; working with PC,	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	Not being able to read literary masterpieces anymore because of the confusion of all the characters

activities ICF d166 & d9200	playing computer games	To make - cross words - word seekers To read magazines - in other languages - Geographic or historic magazines To read fiction books To read non-fiction books - psychology, philosophy, religion - professional literature	
Craftwork and arts ICF 6500 & d9203	Knitting, sewing, repairing clothes, like reattaching buttons and fasteners; painting, sculpting	To sew To tailor clothes To repair clothes To knit (sweaters, pull over's)	When tailoring new pants, making the same leg twice
Complex economic activities or transactions ICF d865	The use of bank cards, 'money out the wall', PC-banking, trading in commodities	To take money out the wall To transact financial papers (savings certificates) or trade in commodities To invest	Using an insurance card instead of a credit card while trying to pay electronically and thereupon not remembering the code anymore
To communicate by using devices or techniques ICF d360	Use of cell phone, e-mail	To use cell phone To use email To write letters	Blocking the cell phone completely, by striking the wrong key and not being able to unlock it
Sports ICF d9201	Informal or organized sports: group activities and sporting on your own (e.g. fishing)	To do gymnastics (in group) To swim (in group) To do aqua gym To use a home trainer To sail To fish To dive To do Yoga To play golf To drive a bike To play billiards or snooker	Problems with sailing because the timing of handling the sails (rising and hoisting)isn't right anymore
Transportation by motorized vehicles ICF d475	Driving a car, motorcycle	To drive a motorized vehicle	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

Leisure activities, socializing ICF d9205	Activity only for amusement or relaxation, with a social component (e.g. go out for diner)	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 ICF d9202 & d810	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 ICF d920	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 ICF d660 & d6506	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 ICF d650	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 ICF d855	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

		To help in a egg factory (sorting eggs) To write educational books (on geography) To work in Social Welfare: to organize the mailing in the home To maintain a fishing pool To trim dogs To have some clients for insurances (from his professional period) To work in the library: to register new books To manage the rent of apartments To work in the family business, doing the office, telephones, shops, making invoices, etc. To work for the priest and church community To deliver the club magazine to the members of the club To be responsible for the local community of the club (visit ill persons, membership, collecting fees, …) To organize activities such as art exhibition, choir, card clubs… To help when the local government organizes dinners	
Engagement in organized social life ICF d910	Active participation in organized communities or societies by taking part in meetings, being member of the board, organizing activities for others or by participating in organized activities like short trips and coffee moments	To be member of - clubs for retirees - debating clubs - think tanks To take part in meetings To be member of the board To organize activities for others To participate in activities organized by others - coffee moments - parties - trips To be responsible for a local area	Problems to engage actively in a meeting because 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