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RESEARCH ARTICLE



Cognitive impairment in daily life (CID): A double-faced instrument to detect changes and impairments in activities of daily living for people with suspected cognitive impairment

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ABSTRACT

Background: Assessment of cognitive function and its consequences for activities of daily living is an important part of a dementia evaluation. To describe patients' functional impairment accurately, a feasible instrument is needed. The Cognitive Impairment in Daily Life (CID) is an instrument developed with that purpose.

Aim: To describe and compare self- and proxy-reported difficulties in everyday life in patients undergoing a dementia investigation, measured by CID. A secondary aim was to compare the results between those who were diagnosed with dementia versus those without dementia.

Method: Self- and proxy-reported data using CID in 77 cases in dementia investigations. Of those, 32 were diagnosed with dementia and were compared to those without dementia ($n = 45$). Descriptive statistics.

Results: When comparing self-reported and proxy-reported activity problems, most activities differed significantly. Proxies reported more difficulties than patients did. When comparing no dementia and dementia groups, significant differences were shown regarding initiative, planning and performance but not for memory and attention estimated by the patient themselves. Proxies differed significantly from patients in all tasks.

Conclusion: Overall, proxies reported that patients had more difficulties than patients reported themselves. The CID seems to be usable in dementia investigations and the results highlight the importance of involving both patients and relatives.

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Introduction

Dementia is a syndrome caused by neurodegenerative diseases and means that the person has a cognitive decline that interfere significantly with everyday life. At an early stage, cognitive impairment is less noticeable and not always evident in social context. This cognitive decline probably starts years before the specific dementia diagnose is evident [1]. The persons lack of awareness in different areas such as cognitive decline, functional ability or social ability and changes in personality can make the diagnostic process complicated to handle [2] as well as the stigma that dementia has sometimes [3]. The prevalence of dementia in Sweden is estimated to 150 000 and predicted to double in 2050 and the cost is rising [4].

Today, there is no cure available for dementia and the disease often effects both the individual and the family. However, there are efforts to be made for both the person and the family to maintain or improve quality of life and reduce burden for informal carers, with medical as well as psychosocial interventions. Assessment of cognitive impairment and the ability to perform activities of daily living is therefore important in the evaluation of dementia [5]. This is not only a diagnostic issue, but also important in order to plan and give treatment and support to the individual and the family. When assessing the ability to perform activities of daily living professionals need to know how cognitive impairment affects the person's occupational performance in order to suggest

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interventions to facilitate everyday life. An evaluation of the influence of cognitive perceptual impairments on activities of daily living, instrumental activities of daily living (IADL), education, work, leisure and social participation are within the role of the occupational therapist [6]. Activities of daily living (ADLs) can be divided into basic; b-ADL (includes more personal activities such as personal hygiene, dressing and transferring also sometimes referred as PADL i.e. personal ADL in literature); IADL, which refers to activities that are related to independent living in the community, such as managing finances, medications, transportation, household activities. The third area are advanced activities (a-ADL); meaning activities that are beyond independent living and more for recreational purposes, such as taking part in a volunteer job, organised leisure activities, or meetings [7,8].

As previously described in other studies, more cognitively demanding activities (complex activities) are affected in the early stages of dementia [9–11]. Certain activities are known to be affected early already in patients with Mild Cognitive Impairment (MCI) such as problems with medication intake, financial capacity, telephone use, keeping appointments, finding things at home, and using everyday technology [12]. There are also emerging data that advanced ADL (a-ADL) might be affected before IADL [13]. This is also a question of how one defines activities of daily living and what is included in this concept and the different ADL areas. ADL instruments and their items are heterogenous [14]. Terms such as ‘functional cognition’ and ‘everyday cognition’ are also used in the literature and can be seen as indirect measures of the ability to perform everyday activities [15,16]. Instruments for assessing IADL and a-ADL have been developed in Belgium and are shown to have good validity in discriminating between cognitively healthy controls, MCI and persons with Alzheimer’s disease (AD) [17,18]. Instruments for measuring the use of everyday technology have also been shown to have good validity [19]. However, none of these separates cognitive tasks in the included items/activities. The Cognitive Impairment in Daily Life (CID) is an instrument developed for that reason, as described elsewhere [20]. CID includes activities from the whole ADL spectra (b-ADL-a-ADL). CID has been developed in different steps and proven to have a good content validity with a CVI index of 0.83 and in a pilot study a good internal consistency with a Cronbach alpha of 0.79 [20]. The instrument has thereafter been further adjusted and this study present the first data from the

adjusted version with 92 items [20]. A qualitative study also confirmed that many of the activities included in the CID are activities in which people with MCI or dementia have experienced changes [21]. Another study using mixed method concluded that it is important to interview the person with a structured everyday life measure to catch the persons own thoughts of performance [22]. The CID is also translated into Dutch and adapted to suit patients with acquired brain injury (ABI) and seems to be appropriate for differentiating between these patients and cognitively healthy controls [23]. The CID assessment is performed *via* an interview with the patient (self-report) and as a questionnaire or interview with a close relative (proxy-report). In this study we wanted to investigate further which activities are affected for people with or without dementia and whether and how self-reported and proxy-reported data differ.

Aim/objectives

To describe and compare self- and proxy-reported difficulties in everyday life in patients undergoing a dementia investigation, measured by CID. A secondary aim was to compare the results between those who were diagnosed with dementia versus those without dementia.

Material and methods

Participants

Patients were consecutively recruited from seven memory investigation units (including both specialist and primary care units) in the southeast healthcare region of Sweden. Inclusion criteria were persons that either themselves or a relative or a health care personal had initiated a dementia assessment. They had to be able to perform the interview in Swedish. All patients included in the project came to the investigation unit for a dementia assessment. Study participants were asked to take part in the study as an extended part of their ordinary investigation. The participants would later be divided into two groups: dementia and no dementia. The dementia group included patients who had received one of the following dementia diagnosis according to the codes in the Swedish version of ICD10 criteria [24]; F00 dementia in Alzheimer’s disease, F01 vascular dementia, F02 dementia in other diseases classified elsewhere (frontotemporal dementia and mixed dementia), F03 unspecified dementia (Table 1). The second group no dementia where patients with MCI according to

Table 1. Sociodemographic data of participants.

Variable	All <i>n</i> = 77	No dementia <i>n</i> = 45	Dementia <i>n</i> = 32	<i>p</i> Value
Patients, age m (SD)	73.8 (8.2)	73.6 (8.6)	74 (7.8)	0.937
Sex <i>n</i> (%)				
Male	40 (51)	21 (46.7)	19 (59.4)	0.271
Female	37 (48)	24 (53.3)	13 (40.6)	
SES (%)				
Low	36 (46.8)	20 (44.4)	16 (50)	0.991
Intermediate	21 (27.3)	14 (31.1)	7 (21.9)	
High	17 (22.1)	11 (24.4)	6 (18.8)	
Education (%)				
Low	38 (50.7)	20 (44.4)	18 (60)	0.257
Medium	20 (26.7)	14 (31.1)	6 (20)	
High	17 (22.7)	11 (24.4)	6 (20)	
MMSE m (SD)	24.9 (4.2)	26.8 (2.4)	22.4 (4.7)	0.003
Range	11–30	21–30	11–29	
Diagnoses (<i>n</i>)				
Alzheimer's disease			18	
Mixed dementia			1	
Vascular dementia			3	
Dementia UNS			1	
Frontotemporal dementia			1	
Mild Cognitive Impairment		18		
No Cognitive Impairment		27		
Proxies				
Spouse	55 (71)			
Child	18 (23)			
Close friend	4 (6)			

Age and MMSE = T-test.

Gender = χ^2 .

SES and Education = Mann Whitney U test.

ICD10 coded as F067 [24] or no cognitive impairment (R418). If the patient agreed a relative (a proxy) was also invited to take part in the study and rate the CID as a proxy. In Swedish dementia investigation it is strongly recommended to involve a close relative in order to get anamnestic history [5]. Ninety-eight patients consented to take part in the study; out of those, 77 had a relative that consented to take part in the study as a proxy. In total 77 patients and their proxies was therefore included in the analyses. The proxy was chosen by the patient to be part of the evaluation. The majority were spouses, thereafter children and in a few cases close friends. Sociodemographic data of participants and cognitive test results are shown in Table 1.

Instrument

The CID is a double-faced instrument that can be used as a self-reported and/or proxy-reported measure of the ability to perform activities of daily living in patients with suspected cognitive impairment or dementia. The interview is semi-structured, and a dialogue is held about the included activities and tasks. CID includes 23 activities divided into 92 tasks (Supplementary Appendix). The 92 tasks are sorted by cognitive components such as initiating, planning, performance, remembering, paying attention and time

perception. The rating scale used has three grades where the tasks are graded as: 0 = No difficulty (the person perceives themselves as completely independent, performing the task as before), 1 = Some difficulty (the person perceives themselves as able to perform the task as a whole or in part but needs extra time or some assistance, and the performance is slightly different from the person's previous ability), 2 = Great difficulty (the person perceives themselves as having great difficulty in performing the task, performs the task incorrectly, or poses a risk to him/herself or the environment; a clear difference from the person's previous ability is evident). A box for 'Don't know/cannot judge' is also included. The same rating-scale were used by proxies, as they rated whether they perceived the person who were under evaluation for dementia as having difficulties with the tasks or not. A total sum was calculated with a score ranging from 0 to 184, the higher scores the more perceived difficulties.

Data collection

Primary care provided 40 cases and specialist settings 37 cases. Ten occupational therapists and one nurse specialised in dementia working in the investigation units took part in the data collection and performed interviews with the patients and their proxies. Data collection took place from 2013 to 2015. The mean time for a patient interview was 33 min (range 10–60 min). The study was approved by the Regional Ethical Review Board in Linköping, Sweden (2012/160-31). Written informed consent was given by both patients and proxies.

Statistics

Descriptive statistics were calculated from sociodemographic data (Table 1) and Student's *t* test for comparisons of total sum of scales (Tables 1 and 2). Education was categorised in terms of low (0–9 years), medium (10–12 years) or high (≥ 13 years) and socio-economic status was categorised by low, intermediate or high according to Dutton and Levin [25], and these data were analysed using Mann Whitney U test.

Difficulties in each activity were dichotomised into 'No difficulties' (in any of the task included in the activity) or 'Difficulties' (in any of the tasks included in the activity). Tasks were dichotomised into 'No difficulties' or 'Difficulties'. χ^2 test was used for comparisons between self-rated and proxy-rated scoring and between dementia group and no dementia group.

Analyses were performed comparing patients in the dementia group with those with no dementia. The

group no dementia included patients that did not receive a cognitive diagnosis during data collection time and those diagnosed as MCI. The group that did not receive a diagnosis of any cognitive condition did not differ from the MCI group in analyses thus they were analysed as a whole group (no dementia).

Correlation analyses (Spearman's rho) between MMSE and CID resulted in a low correlation coefficient for patients' scoring (-0.183) and somewhat higher for proxies' scoring (-0.416).

Results

Throughout, proxies reported difficulties more frequently than patients did. The CID total sum results showed significant differences between groups no dementia and dementia for both self-rated and proxy-rated total sum (Table 2).

Comparisons between self-reported and proxy-reported data

When comparing the frequencies of activities that difficulties were reported in, most activities (18 out of

23) differed significantly between self-reported and proxy-reported ratings (Table 3). Proxies reported more difficulties than the patients did. The activities that most patients experienced difficulties in were handling conversations (61%), leisure activities (49%), using the telephone (48%), shopping (47%) and reading (44%). Proxies reported most difficulties with transportation/traveling (82%), conversations (78%), television (71%), contact with society (69%) and contact with family and friends (68%).

Significant differences were also shown in all cognitive tasks between self-rated and proxy-rated scorings (Table 4).

Comparisons between patients with no dementia and dementia

When comparing the frequencies of activities with self-reported problems in for patients without dementia and persons with a diagnosis of dementia, the only activities that differed among patients were transportation ($p=0.002$), contact with society ($p=0.001$), telephone ($p=0.009$), shopping ($p=0.020$) and meals ($p=0.002$). The proxies' scoring showed significant differences between no dementia and dementia groups in 19 of 23 activities. Those were in all activities except for work, driving a car and using a computer (Table 5). One activity (toilet visits) was not applicable in the analyses due to few numbers.

When comparing self-reported scores between no dementia and dementia groups, significant differences

Table 2. Test result total sum CID.

CID total sum	All <i>n</i> = 77	No dementia <i>n</i> = 45	Dementia <i>n</i> = 32	<i>p</i> Value
Self-report, <i>m</i> (SD)	14.5 (13.3)	9.9 (9.1)	21 (15.5)	0.000
Range	0–61	0–41	0–61	
Proxy-report, (SD)	40 (36.4)	23 (25.5)	64 (36.2)	0.002
Range	0–129	0–121	7–129	

T-test.

Table 3. The number of patients that reported difficulties in each activity versus the number of proxy-reported difficulties and level of agreement ($n=77$).

Activity	Self-reported difficulties <i>n</i> (%)	Proxy-reported difficulties <i>n</i> (%)	χ^2	<i>p</i> Value
Work	5 (6)	6 (8)	0.01	n.s
Leisure activities	38 (49)	43 (56)	0.65	n.s
Transportation/travel	26 (34)	63 (82)	36.4	<0.001
Driving	15 (20)	26 (34)	4.0	0.045
Handling finances	25 (33)	46 (58)	11.5	<0.001
Handling medication	27 (35)	37 (48)	2.7	n.s
Contacts with society	27 (35)	53 (69)	17.6	<0.001
Contacts with family and friends	33 (43)	52 (68)	9.5	0.002
Conversations	47 (61)	60 (78)	5.2	0.022
Reading	34 (44)	45 (58)	3.1	n.s
Writing/notes	20 (26)	33 (43)	4.9	0.027
Computer	12 (16)	33 (43)	13.8	<0.001
Television	28 (36)	55 (71)	19.1	<0.001
Telephone	37 (48)	56 (73)	9.8	0.002
Cooking	33 (43)	47 (61)	5.1	0.024
Shopping	36 (47)	49 (64)	4.4	0.035
Cleaning	14 (18)	40 (52)	19.3	<0.001
Doing laundry	4 (5)	24 (31)	17.5	<0.001
Meals	9 (12)	34 (44)	20.2	<0.001
Mobility	26 (34)	41 (53)	5.9	0.015
Clothing/Dressing	3 (4)	45 (58)	53.4	<0.001
Personal hygien	6 (8)	28 (36)	18.3	<0.001
Toilet visits	0	4 (5)	NA	NA

Table 4. Frequencies of difficulties in cognitive tasks, self-reported compared to proxy-reported rating ($n = 77$).

Cognitive tasks (total number of activities including the task)	Self-reported difficulties, $n = 77$	Proxy-reported difficulties, $n = 77$	χ^2	p Value
Initiative (23)	227	541	163.9	0.000
Planning (12)	101	301	127.2	0.000
Performance (22)	245	550	152.9	0.000
Attention (8)	79	182	51.6	0.000
Memory (19)	277	586	156.9	0.000
Time perception (7)	23	93	47.3	0.000

Table 5. Proxy-reported difficulties in each activity categorised by no dementia ($n = 45$) and dementia ($n = 32$).

Activity	Proxy-reported difficulties n (%)	Proxy-reported difficulties n (%)	χ^2	p Value
	No dementia, $n = 45$	Dementia, $n = 32$		
Work	3 (7)	3 (9)	0.2	n.s
Leisure activities	17 (38)	26 (78)	14.3	<0.001
Transportation/travel	32 (71)	31 (97)	8.3	0.004
Driving	12 (27)	14 (44)	2.4	n.s
Handling finances	18 (40)	28 (88)	17.5	<0.001
Handling medication	15 (33)	22 (69)	9.4	0.002
Contacts with society	26 (58)	27 (84)	6.2	0.013
Contacts with family and friends	23 (51)	29 (91)	13.3	<0.001
Conversations	29 (64)	31 (97)	11.4	<0.001
Reading	18 (40)	27 (84)	15.2	<0.001
Writing/notes	11 (24)	22 (69)	15.0	<0.001
Computer	19 (42)	14 (44)	0.02	n.s
Television	26 (58)	29 (91)	9.9	0.002
Telephone	26 (58)	30 (94)	12.2	<0.001
Cooking	20 (44)	27 (84)	12.5	<0.001
Shopping	24 (53)	25 (78)	5.0	0.026
Cleaning	17 (38)	23 (82)	8.7	0.003
Laundry	10 (22)	14 (44)	4.0	0.044
Meals	15 (33)	26 (58)	17.2	<0.001
Mobility	17 (38)	24 (75)	10.4	0.001
Clothing/dressing	19 (42)	26 (81)	11.7	<0.001
Personal hygien	11 (24)	17 (53)	6.6	0.010
Toilet visits	1 (2)	3 (9)	NA	NA

Table 6. Frequencies of self-reported difficulties in cognitive tasks, no dementia ($n = 45$) compared to dementia ($n = 32$).

Cognitive tasks (total number of activities including the task)	Self-reported difficulties, No dementia, $n = 45$	Self-reported difficulties, Dementia, $n = 32$	χ^2	p Value
Initiative (23)	82	145	18.7	0.000
Planning (12)	34	67	11.4	0.000
Performance (22)	108	137	3.7	0.054
Attention (8)	41	38	0.1	ns
Memory (19)	137	140	0.09	ns
Time perception (7)	3	20	NA	NA

were shown regarding tasks of initiative, planning and performance but not in attention, memory, or time perception (Table 6).

However, when comparing proxy-reported scores between no dementia and dementia groups, significant differences were found for all cognitive tasks (Table 7).

Discussion

The CID seems to be helpful in describing what difficulties individuals' experience in their everyday life

and how these experiences might differ between patients and their relatives. This information is often useful in the diagnostic process of dementia. The CID results differs and seem to discriminate between groups with dementia and no dementia. The results show that there are differences in self-rated and proxy-rated difficulties in activities of daily living, which is concordant with previous research [26]. The most interesting finding was that proxies reported considerably more difficulties in everyday life activities than patients did. This highlights the importance of involving proxies in the evaluation of dementia.

Table 7. Frequencies of proxy-reported difficulties in cognitive tasks, no dementia ($n = 45$) compared to dementia ($n = 32$).

Cognitive tasks (total number of activities including the task)	Proxy-reported difficulties, No dementia, $n = 45$	Proxy-reported difficulties, Dementia, $n = 32$	χ^2	p Value
Initiative (23)	186	355	62.3	0.000
Planning (12)	107	194	30.0	0.000
Performance (22)	194	356	51.3	0.000
Attention (8)	69	113	12.5	0.000
Memory (19)	242	344	22.2	0.000
Time perception (7)	28	65	16.1	0.000

Previous research has also shown difference in awareness of disease and awareness of functional deficits and recommend the use of both proxy and self-rated ADL scales [22]. Our study results strengthened this work model in the dementia diagnostic process. From an occupational therapy perspective, it is of great importance to gather information from different sources in order to support both the patient as well as the family.

Also, when comparing how the cognitive tasks were perceived there were significant differences between patients and relatives in all tasks. Patients with dementia perceived significantly more problems with initiative and planning than patients without dementia; again, relatives saw differences in all cognitive tasks. Initiative and planning are executive functions that are known to affect ADL [27].

Both patients and proxies scored conversations to be a problem. Social participation in terms of handling contact with society, family and friends and taking part in leisure activities are also problems among many persons. Using the telephone is another well-known activity that is affected for people with cognitive impairment and this is confirmed in this study [28]. All those activities are important for social participation. Being less active in leisure and social activities has also been seen as risk factors for dementia [29]. This is important for professionals and society when planning for intervention and including people with dementia.

More surprisingly was the finding that there was no significant difference between persons with or without dementia except for handling contact with society, transportation, shopping, telephone, cleaning, and meals. This can possibly be explained by the fact that people with dementia might have more problems with insight [30,31]. Significant differences were seen in 19 out of 23 activities between dementia and no dementia groups as perceived by proxies, and these findings highlight the importance of also including proxies in the evaluation, not only for the diagnostic work but to support the patient and their family careers in the future. There were problems perceived

in all activities in the CID by both patients and proxies. Personal activities were less common but some individuals, even those without dementia, perceived problems with activities such as dressing and personal hygiene. The fact that those activities can be affected even in MCI stages has been reported elsewhere [21,32]. A questionnaire aimed to evaluate out-of-home participation for people with Dementia has been developed [33]; nevertheless, in a clinical evaluation of dementia it is important to get an overview of the whole situation for the family, including activities performed at home as well as outside home.

Self-assessment has some limitations due to the likelihood that people with cognitive impairment also might have impaired insight [31] and also proxies can have difficulty in grading the changes due to different reasons, as they show gradual adjustments in how they cope with symptom burden [34]. Nevertheless, both self-reported and proxy-reported interviews is the most feasible way to assess effects in everyday life, and together they make an important part of an investigation. Staff also need to have good tools to conduct those interviews. An observation-based assessment of the ability to perform activities of daily living can be of importance and preferable to self- and relative assessment but this is more time-consuming and sometimes people are not comfortable with being observed. A combination of different assessment methods might be the best solution in clinical practice [35]. The CID interview can be supplemented with observation-based method as well, and the patient could be observed in some of the included activities. In clinical work there might also be a possibility to perform the interview with both the patient and a proxy present on the same occasion. This is up to the occupational therapist to assess when it is suitable. The CID is quite extensive in terms of tasks but is not very time consuming. It covers many activity areas; of course, it cannot include all activities for all people, but the objective is to identify those areas in everyday life that are affected and of importance to the person. There are a lot of ADL instruments that have proven to be useful in early stages of dementia

[12]. However, very few of them are validated in or translated for the Swedish care context, and therefore tend not to be used in clinical practice. There is a lack of useful and feasible instruments for this purpose and from this study CID is a usable alternative.

Methodological considerations/limitations

A weakness of the study is that we lack data about the final diagnoses of 27 people. We do know they had cognitive symptoms reported by themselves (subjective), a relative, or a member of the health-care staff, and that they experienced some degree of cognitive impairment. These patients were therefore referred for further investigation. The instrument was used to be a part of the evaluation in a clinical context as intended. A weakness is that data were not blind to the physician who set the diagnosis. The data set is also relatively small and therefore we cannot make any more sub analyses with different diagnoses, for example.

A strength is that the same instrument is used for both patients and proxies. It is important for professionals to get information from both parts, for diagnostic work and when planning for interventions. Large differences in estimation results between patients and close relatives may possibly indicate a lack of insight in the patient, which may be important to pay attention to as well. For the relative (proxy) it is important to be able to share his or her thoughts and experiences of changes and symptoms. This tool can also give professionals information on how they can support relatives so they can be supportive to the person with cognitive impairment in daily life.

Conclusions

Overall, from the answers in the CID instrument, proxies reported that the patient had more difficulties in everyday life than patient reported. Activities often experienced as difficult by both patients and proxies were handling conversations and leisure activities, using the telephone and transportation as well as handling contact with society, family, and friends although to a greater extent by proxies. Patients with dementia reported more difficulties with initiating, planning, and performing activities than patients with MCI did. From the results, the CID instrument seems to be usable in dementia investigations. The results also highlight the importance of involving both patients and proxies, as there are differences in the identification of functional limitations.

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Disclosure statement

The authors report no conflict of interest.

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