

Research Report

Awareness of Functional Status: People with Alzheimer's Disease Abilities to Self-Report Impairment in Activities of Daily Living

Paula Gasparini Emery Trindade^{a,*}, Raquel Luiza Santos^a, Aud Johannessen^{b,c},
Jose Pedro Simões Neto^d and Marcia Cristina Nascimento Dourado^a

^a*Center for Alzheimer's Disease, Institute of Psychiatry, Universidade Federal do Rio de Janeiro, Brazil*

^b*Norwegian Advisory Unit for Aging and Health Vestfold Health Trust, Tønsberg, Norway*

^c*University College of Southeast Norway*

^d*Department of Political Sociology, Universidade Federal de Santa Catarina, Brazil*

Accepted 31 August 2020

Abstract.

Background: Awareness of functional status may underlie specific profiles and differences related to stage severity in individuals with Alzheimer's disease (AD).

Objective: This study aimed to assess self-reported experiences of awareness of functional activity in people with mild and moderate AD.

Methods: This is a mixed methods approach. The qualitative part was conducted through semi-structured interviews concerning the experiences and awareness of deficits in 38 older adults with mild or moderate AD. The quantitative approach included a comparison between groups with regard to concerns of awareness and clinic and demographic data.

Results: Impairment on awareness of disease and awareness of functional deficits was observed even in the mild stages of AD. There was also a noticeable progression of impairments of both kinds of awareness from mild to moderate stage of disease. The majority of participants with mild and moderate AD were partially aware of their functional deficits. Both groups of participants reported some negative impact; however, they were not able to entirely describe their functional status. Also, deficits to recognize the need for help with hygiene and general tasks were observed. Significant differences were found in awareness of need for help with general tasks and awareness of need for help with hygiene tasks.

Conclusion: People with mild and moderate AD may describe their aware of the disease better than specific functional deficits, and most of them can provide some reports concerning to the impact of the disease.

Keywords: Activities of daily living, awareness, cognition, dementia, disease

INTRODUCTION

The extensive impact of Alzheimer's disease (AD) on daily functioning is a core symptom of the disease

[1–3]. Consequently, people with AD, by definition, have an impairment in their functional status and are unable to complete at least one activity of daily living (ADL) [4, 5]. A hierarchical structure was developed to describe different levels of ADLs [6]. Basic ADLs include self-care tasks, such as dressing and bathing. Instrumental ADLs comprise independent living tasks, such as finances, meal preparation, and

*Correspondence to: Paula Gasparini Emery Trindade, MSc, Rua Julio de Castilhos, 87/901 – 22081025 - Rio de Janeiro, Brazil. Tel.: +55 21 99912 1202; E-mail: paulagaspariniemery@gmail.com.

medication management. Advanced ADLs include more complex volitional tasks such as engagement in hobbies and social activities [4, 7]. Individuals with progressive cognitive impairment such as that seen with AD often experience impairments in advanced and instrumental ADLs early in the disease course [5, 8]. Basic ADLs are not impacted until later in the course of the condition [9] and usually deteriorate in the opposite order to which they were acquired in childhood (e.g., bathing, dressing, going to toilet, transfer, continence, and feeding) [6].

One study [9] examined a cohort of 5,874 community-dwelling people aged 65 years and older and supported this theory, finding that instrumental ADLs were more likely to be impaired than basic ADLs in individuals with mild levels of cognitive decline. Another study [1] examined individuals in the early stages of dementia and reported impairments across all ADL types, but predominantly in instrumental ADLs. Thus, AD-related cognitive decline may be considered an important risk factor for functional decline and loss of independence [9].

Unawareness, also termed anosognosia [10], is the denial or inability to recognize impairments in ADLs or cognitive deficits [11] and is a clinical feature of dementia [12]. This unawareness of cognitive and functional deficits may lead to some of the dangerous behavior associated with AD, including motor vehicle accidents, taking repeated doses of medications, and leaving the stove on [13]. These issues are especially evident in complex activities associated with daily functioning [14]. For example, it was found [15] that awareness of declines in daily activities that require executive function (such as completing chores, handling money, and engaging in hobbies) was impaired in amnesic participants and individuals with mild and moderate AD. Similarly, another study [16] found that financial management and driving abilities were not accurately estimated even in participants with mild cognitive impairment compared to cognitive healthy controls. Also, people with AD have been found to have better awareness of memory deficits compared to their own social-emotional functioning [17]. Whereas social and emotional functioning require a variety of judgments, configuring a more complex assessment [17], memory and ADL judgments are more straightforward [18].

The discrepant levels of awareness in different domains of ADL functioning is crucial in determining clinical treatment strategies early in the condition. In particular, recognition of when it is necessary to seek medical care may be difficult for family members

to determine, as individuals with AD are unlikely to request this care themselves due to their unawareness. Healthy cognitive aging involves many changes in brain's size, structure, and functioning, resulting in variable impacts on multiple cognitive domains [19]. Early impairments in functional status have been identified as a predictor of unawareness and a strategy for distinguishing between normal, age-related cognitive changes and pathological decline. Impairment in instrumental ADLs predicts unawareness in late-onset AD, but is less evident in young-onset AD [14]. This may be because people with young-onset AD are more likely to have complex demands (e.g., work), where earlier impairments would be more pronounced and consequential compared to older adults with a relatively simpler daily life. Thus, awareness of functional status may underlie specific profiles and differences related to age of onset and dementia severity in people with AD.

Few studies have focused on qualitative reports of people with AD regarding their own awareness (or unawareness) of ADL functioning and how their existence and everyday lives are affected. Functional abilities in people with AD is frequently assessed by collateral informants or via objective performance-based measures, whereas self-ratings are less commonly employed [20]. A recent study [20] found that the self-ratings of AD individuals with AD perceptions, were closer to objectively assessed mean scores of functional ability than proxy ratings. These findings indicated that self-report may have important clinical value and may assist in determining when assistance with ADLs needs to be provided [20]. In this context, we conducted a study using a similar approach aiming to explore the experience of awareness of functional activities in people with mild and moderate AD. We also compared an objective measurement of functionality with the participants self-report.

METHODS

Design

This was a mixed-methods study including both qualitative and quantitative analyses. The qualitative part of the study involved accounts concerning to the disease process of people with mild and moderate AD.

A semi-structured interview with 23 questions, based on the Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia (ASPIDD) [21,

Table 1
Semi-structured interview

1- Can you identify anything wrong with you? Do you think it may be an illness?
2- Has your routine changed nowadays? How?
3- How do you think the disease influences in your life?
4- Do you ask or need help to perform your tasks? Which tasks? Who helps you?
5- Who takes care of your personal hygiene? How?

22] was conducted with all participants. These 23 questions were employed in a previous study [23] that aimed to assess awareness of disease in general, including awareness of cognitive, relationship, and emotional status domains. The present study aimed to highlight and specifically analyze awareness with regard to ADL functioning. Therefore, only 5 of these 23 questions were selected for evaluation in this study. The first question encompassed awareness of disease, including the recognition of cognitive deficits and their relation to a pathological state. The other questions examined awareness of functional status via the four components of the ADL section of ASPIDD: routine changes, help to perform tasks, personal hygiene, and influence of the disease in life.

Table 1 contains the questions of the semi-structured interview.

The quantitative approach included a comparison between groups on clinical/demographic variables as well as their awareness levels.

Participants

This study evaluated a sample of 38 people with AD (19 female) recruited at the Center for Alzheimer's Disease and Related Disorders, Institute of Psychiatry, Universidade Federal do Rio de Janeiro, Brazil. All participants were diagnosed with Major Neurocognitive Disorder due to Possible or Probable AD according to the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition [24]. The clinical diagnosis of AD was based on a clinical interview with the person with AD and caregiver, cognitive screening tests, laboratory tests, and imaging studies. We only included individuals with mild and moderate dementia based on the Clinical Dementia Rating (CDR) values of 1 or 2 [25], and Mini-Mental State Examination (MMSE) scores ranging between 12 and 26 [26]. CDR evaluates dementia severity and MMSE evaluates cognitive performance through cognitive tasks including spatial and temporal orientation, immediate memory, attention, calculation, recall memory, and language. We used the Pfeffer Functional Activities Questionnaire (PFAQ) as

a collateral report to compare with the participant self-report. The PFAQ is a caregiver-reported ADL inventory that provides a measurement of functionality. It comprises 10 questions that evaluate the independence of performance in several instrumental ADLs [27], including financial management, shopping, heating water and shutting off the stove, meal preparation, keeping track of current events, watching news reports and discussing about them, remembering commitments, remaining oriented while walking outside the neighborhood, medication management, and being at home alone [28]. Scores of this assessment range from 0 to 30 points, with higher scores indicating worse functional impairment [27].

Exclusion criteria involved a history of alcohol abuse, aphasia, epilepsy, and head trauma. Interviews were conducted individually with each participant by a researcher trained in interview techniques. All people with AD were receiving medical treatment at the time of the interviews including cholinesterase inhibitors.

Table 2 details the clinical and demographic characteristics of the sample.

Ethics

The ethical guidelines outlined in the revised Declaration of Helsinki (World Medical Association, 2013) were followed. The study was approved by the Ethics Committee of the Institute of Psychiatry of the Universidade Federal do Rio de Janeiro, in Brazil. All participants and familial caregivers provided their written consent before the interview.

Analyses

The modified version of Grounded theory (Corbin and Strauss, 2008) [29] method was applied. The intention was not to devise a new theory, but just to obtain more details about individuals' experiences and their need for support. This method is appropriate for examining experiences related to personal development and social interactions. Interviews were recorded, transcribed, and analyzed, focusing on

Table 2
Clinical and demographic data

Participants with AD	Mean (SD)		<i>p</i>
	CDR 1 (<i>n</i> = 17; 45%)	CDR2 (<i>n</i> = 21; 55%)	
Age	69.65 (5.51)	72.95 (9.82)	0.114
Years of education	9.88 (4.82)	8.71 (4.85)	0.6
Years since dementia diagnosis	3.21 (1.43)	5.22 (2.26)	0.004
Number of children	2.76 (2.17)	2.1 (1.48)	0.577
MMSE	22 (2.65)	18 (3.43)	<0.001
PFAQ	17 (6.88)	21 (8.18)	0.004
<i>Civil status n (%)</i>			0.059
Married	13 (76)	11 (52)	
Widowed	2 (12)	8 (38)	
Single, never married	2 (12)	0 (0)	
Separated or divorced	0 (0)	2 (10)	
<i>Gender n (%)</i>			0.595
Female	11 (65)	13 (62)	
Male	6 (35)	8 (38)	
<i>Presence of Caregiver n (%)</i>			0.447
Yes	16 (94)	21 (100)	
No	1 (6)	0 (0)	
<i>Financial Situation n (%)</i>			0.906
Retired/pension/licensed at work/Health insurance	11 (65%)	15 (71%)	
Dependent on their caregiver	5 (29%)	5 (24%)	
Unemployed/ Do not work for a year	1 (6%)	1 (5%)	

AD, Alzheimer's disease; CDR, Clinical Dementia Rating; CDR1, mild dementia; CDR2, moderate dementia; SD, standard deviation; MMSE, Mini-Mental State Examination; PFAQ, Functional Activities Questionnaire.

people with AD self-reported experiences with regard to awareness of functional deficits and their disease status. Two authors (P.G.E.T. and M.C.N.D.) read all the interviews and applied the first "open coding" in order to discover relevant themes regarding specific episodes of awareness and narratives about context, actions, reactions, emotions and reflections. This initial open coding consisted of watching for relevant themes by reading all the interviews open-mindedly and simultaneously. Next, an "axial coding" stage comparing the themes were undertaken, aiming to find the most essential higher-level themes for the whole group. Subthemes and variations emerged in this process. Discussions between the researchers were undertaken in order to reach agreement regarding these higher-level themes. During this process, the themes were continuously related to empirical material by researchers, who analyzed it vertically, while simultaneously referring back to the information provided by the informants. In line with the method's comparative approach, horizontal analyses were made from comparisons between the informants' situations and experiences of all the informants. Thus, the open and axial coding stages were intertwined, in line with recommendations from Corbin and Strauss emphasize ([29], p. 198). Temporal changes in how dementia impacted participant's functioning and life circumstances was

also examined in the empirical analysis. This overall process resulted in a result, a complete, hierarchically organized summary list of topics and themes. When investigators reached an agreement upon a final set of topics, all the transcripts were examined accordingly, resulting in a compilation of the full list of interview excerpts related to each topic. Afterwards, an interpretative process was undertaken, aiming to integrate these excerpts and/or challenge current scientific understanding of awareness of functional deficits.

For the quantitative analyses, we used Fisher's exact test and Chi-square test of independence to compare the mild and moderate AD groups with regard to clinical/demographic variables and their awareness of disease status and ADL functioning. For all analyses, the α -level was set at $p < 0.05$.

RESULTS

Two areas of awareness (functional deficit and the disease as a whole) were investigated across dementia severities (i.e., CDR 1 or CDR 2). The first question of the interview was selected to represent awareness of disease, and the other four questions represented awareness of functional deficits or changes in ADLs.

Categories were created to account the domains of functioning that were addressed by the participant responses.

CDR 1 ($n = 17$): Mild AD participants

Awareness of the disease

More than half of the participants in mild stage AD (53%; $n = 9$), presented preserved awareness of the disease, and 41% ($n = 7$) presented partially impaired awareness of the disease. Only one participant (representing 6% of the sample) was unaware of the disease.

Two participants who were aware of the disease described their perception of the condition, with a focus on memory problems:

"I'm starting to forget things. I worry if I turned off the fan and I already let the food burn in the stove. This has happened for about 2 years. [How do you think the disease influences in your life?] I do not cook anymore, it is cheaper, but I was afraid of causing some serious accident." (E., female, social worker, 75 years old, Pfeffer = 16).

"[Can you identify anything wrong with you?] Because I'm so forgetful, I forget everything! I go to the street to buy something and at the end I buy what was not to buy". (J., female, housewife, 66 years old, Pfeffer = 21).

From the mild AD sample, one participant (6%) had to be questioned about memory impairments because he did not initially acknowledge it. Two participants (12%) attributed their memory impairments to non-AD causes, including depression ($n = 1$) and a prior history of aneurysm ($n = 1$).

Awareness of functional status

The majority of the participants (71%; $n = 12$) exhibited partially impaired awareness of functional status and 29% ($n = 5$) were unaware of their functional deficits. Some participants demonstrated conflicting perceptions about the changes in their routines:

"No, I still do the same things: gym, Tai Chi Chun, sewing, keyboard classes. I do not cook anymore, because I was afraid to provoke a serious accident." (E., female, social worker, 75 years old, Pfeffer = 16).

"The problem of forgetting disturbs my life, I am a lawyer, I work and I cannot follow the judicial

processes. At home, it is more or less, because everything is controlled by my wife." (W., male, lawyer, 76 years old, Pfeffer = 18).

One participant demonstrated no awareness of changes in his functioning:

"That's the same thing. I'm taking a professional license." (A., male, teacher, 66 years old, Pfeffer = 18).

Out of the 94% of participants in the CDR 1 group who were aware or partially aware of the disease, 29% ($n = 5$) were not aware of functional deficits. When asked if she could identify something wrong with her, one participant expressed:

"Forgetfulness, because of my husband's insistence, I realized that I am repeating things and I am angry because of the disturbance in my head. Empty head, dizziness." (I., female, housewife, 82 years old, Pfeffer = 24).

In contrast, the same participant manifested lack of awareness about changes in ADLs:

"I am no longer detailed and organized as before. I would like to be the same as before. Now I do things more moderately. Routine has decreased. I did not stop doing what I have to do, and make all by myself, I iron I cook and I wash." (I., female, housewife, 82 years old, Pfeffer = 24).

In addition, most participants with impaired ADLs showed difficulties describing the severity of their conditions because 35% ($n = 6$) did not detail deficits in any ADLs, 47% of them ($n = 8$) mentioned impairment in only one ADL, and 18% ($n = 3$) mentioned difficulties in two ADLs.

Participants with mild AD considered themselves negatively impacted by their functional deficits in the following domains:

- a. Emotional state (the emergence of sadness, fear, apprehension, distress), work/managing finances, changes in personality, and contentment with memory – 3 participants.
- b. Emotional state (motivation) – 2 participants.
- c. Autonomy, activities, communication, cooking, sleep – 2 participants.
- d. Relationships, sexuality, orientation, needs, entertainment, organization, financial situation, comfort – 1 participant.

One participant described how she felt changes in personality caused by the deficits in ADLs:

"I quit going to the bank, to the supermarket, or to go out with people anymore." (S., female, teacher, 67 years old, Pfeffer = 18).

One participant mentioned the impact on communication:

"[Can you identify anything wrong with you?] Dizziness, once I got lost in the neighborhood, where I have been living for 30 years. I also feel very forgetful. I only remember what I want after a while. I forget what I want to say and this is what most annoys me." (J., male, 73 years old, general manager, Pfeffer = 19).

Another participant described changes in financial management and personality:

"I lost control over the financial situation, I became disorganized, I don't remember where I put things." (J., male, bookkeeper, 77 years old, Pfeffer = 1).

Another participant experienced changes in motivation and work:

"I'm losing my memory, I forget things, I have never been like this. I was dismissed from work because I began to confuse patient's slides. [How do you think the disease influences in your life?] I planned to work until I die, and now I am inactive. Work was very important to me, my motivation." (M., female, doctor and dentist, 63 years old, Pfeffer = 27).

A participant described impact in work efficiency, lack of activities, and sexuality:

"I can't work anymore because of the failures. Everything I managed, I passed to her (wife). Slowly things have changed, sex has changed. I only wash the dishes, I would like to do something." (O., male, lawyer, 71 years old, Pfeffer = 17).

Mild AD attributed their functional declines to changes in:

- Memory - 12 participants.
- Motivation, carefulness - 2 participants.
- Hygiene - 1 participant.

A participant described memory changes:

"I forget things. I try hard to recover, then, after three days, I remember some things, but forget others. I am concerned about my own condition,

my head failure, I get anxious in the kitchen worrying if I burn things. I have never been forgetful before, I have never made mistakes." (G., female, administrative assistant of healthcare, 64 years old, Pfeffer = 15).

CDR 2 ($n = 21$): Moderate AD participants

Awareness of disease

One-third of participants (33%, $n = 7$) demonstrated a preserved awareness of their disease status, whereas 52% ($n = 11$) had partially impaired awareness and the remaining three participants (14%) were considered unaware of the disease.

Some participants expressed partial awareness about their condition, including memory deficits:

"I feel no need to attend this place (hospital). Forgetful, I'm forgetful, not that much, but I am!" (S., female, 80 years old, housewife, Pfeffer = 23).

"[Can you identify anything wrong with you?] Because I had a problem with a grandson who died, and now I cannot do anything anymore [came to take care of sadness]. [How about your memory?]. Worst of all, I forget a lot of things, which I have to do, but it is kind of working out." (A., female, 67 years old, housewife, Pfeffer = 27).

From the moderate AD sample, 24% ($n = 5$) did not immediately identify a problem related to memory and had to be questioned further. Moreover, four participants (19%) reported cognitive symptoms but attributed their condition to other causes, including aging ($n = 1$; 5%), genetics ($n = 1$; 5%), sadness ($n = 1$; 5%), and labyrinthitis ($n = 1$; 5%).

Awareness of functional deficits

Eight participants (38%) were unaware of deficits in ADL functioning, and the remaining 62% ($n = 13$) exhibited partial awareness. Two participants who were partially aware described the changes they noticed:

"I don't cook anymore. When there is a visitor at home, it is for my husband, not for me." (M., female, housewife, 73 years old, Pfeffer = 21).

"Yes, because I get dependent. I turn to my caregiver a lot. I'm not working anymore and went to live with my sister." (L., female, educational adviser, 84 years old, Pfeffer = 20).

Out of the 86% of the people with CDR 2 who were aware and partially aware of the disease, 38%

($n = 8$) were not aware of any functional deficits. One participant who was partially aware of the disease but not changes in ADLs explained her condition:

"[Can you identify anything wrong with you?] I came here because I was sick and my husband thought I needed to treat myself. [What did you feel?] Memory loss. I want to remember some things and I can't remember in details, only superficially. Now we are talking here and right away I do not remember the subject matter of the conversation". [Has your routine changed nowadays?] "I think there was no alteration, it's almost the same thing". [How do you think the disease influences in your life?] "It does not affect my rhythm, which is normal". [Do you ask or need help to perform your tasks? Do you ask for help?] Depends on the task. I like help, but I do not need." (R., female, housewife, 83 years old, Pfeffer = 2).

All participants in the moderate AD group demonstrated a limited awareness regarding the severity of their functional deficits. Almost half of the participants were not able to describe any deficits in functioning (48%; $n = 10$). Six participants (29%), mentioned impairment in only one ADL, and five participants (24%) mentioned impairment in two ADLs.

Participants with moderate AD acknowledged the negative impacts of functional deficits in the following areas:

- Work/managing finances – 5 participants.
- Emotional state (emergence of fear, distress, and worries) – 3 participants.
- Autonomy, isolation, relationships, moving house, needs, activities, sleep, lack of courage – 2 participants.
- Contentment with memory, orientation, changes in personality, remembering commitments, cooking – 1 participant.

A participant described the impact of his condition on the lack of activities, distress, and fear:

"[Can you identify anything wrong with you?] My head is not good, I forget things, my head gets uninvolved, I forget things a lot, I put things in one place and then I forget. I got lost once. [Has your routine changed nowadays?] Yes, there is nothing good for me, thank God I have a very good partner, but I do nothing. [How do you think the disease influences in your life?] Lately I have been a little depressed, I want to do something,

start to think, get scared and I do not do". (G., male, trader, 73 years old, Pfeffer = 2).

The participant with moderate AD who described the most severe deficits in functionality acknowledged the impact on personality, sleeping, loss of autonomy, distress, lack of activities, and work:

"[Changes] Yes, I am not a taxi driver anymore, now I sleep a lot, walk on the beach, I wait for her (wife) at night. [Impact] It is disturbing because I am feeling very lost, I do not know how to do anything alone. [Ask for help?] I feel like a cat whose mother has to help." (A., male, 71 years old, taxi driver, Pfeffer = 25).

Moderate AD attributed their functional declines to changes in:

- Memory – 12 participants.
- Depression or sadness, hygiene – 3 participants.
- Fear, "bad head", motivation – 2 participants.
- Age, drowsiness, eyesight, labyrinthitis, stress, lack of courage – 1 participant.

One participant was aware of changes in his routine, but related his deficits to age and motivation rather than due to AD:

"My wife thought it was better to treat myself here, I do not feel anything, what I feel is because of my age. I'm retired, worked 40 years in a firm. [Changes in routine] It has changed, because I do not work anymore, and I miss it. [Impact] It is making me unwilling to do anything. I already have worked too hard." (A., male, 66 years old, watchman, Pfeffer = 24).

Another participant who was aware of functional deficits attributed her condition to memory:

"[Can you identify anything wrong with you?] I think forgetting is the main thing, I forget things, I forget dates, I forget places and people with whom I do not have close relationships. [Impact] It bothers when I want to remember something and I'm not successful. [Ask for help?] Yes, to put my house in order, at the kitchen, to cook." (I., female, 75 years old, dressmaker, Pfeffer = 2).

Differences between groups

Table 3 displays the comparisons between groups in awareness of disease and domains of awareness of functional status.

Table 3
Differences in awareness between mild and moderate people with dementia

Concern/Disease stage	CDR 1 (<i>n</i> = 17; 45%)			CDR 2 (<i>n</i> = 21; 55%)			<i>p</i>
	Aware	Partially aware	Unaware	Aware	Partially aware	Unaware	
Disease/forgetfulness	9 (53%)	7 (41%)	1 (6%)	7 (33%)	11 (52%)	3 (14%)	0.42
Changes in routine	0 (0%)	11 (65%)	6 (35%)	0 (0%)	13 (62%)	8 (38%)	0.565
Impact of the disease	0 (0%)	13 (76%)	4 (24%)	0 (0%)	13 (62%)	8 (38%)	0.273
Need for help with general tasks	0 (0%)	3 (18%)	14 (82%)	0 (0%)	11 (52%)	10 (48%)	0.029
Need for help with hygiene tasks	0 (0%)	1 (6%)	16 (94%)	3 (14%)	6 (29%)	12 (57%)	0.033
Functional status as a whole	0 (0%)	12 (71%)	5 (29%)	0 (0%)	13 (62%)	8 (38%)	0.416

Differences between groups were found concerning to some domains of awareness of functional status. There was a significant difference in awareness of need for help with general tasks ($p=0.029$) and awareness of need for help with hygiene tasks ($p=0.033$), with lower awareness in the mild dementia group for both variables. However, no significant differences were observed with regard to awareness of disease ($p=0.42$), awareness of changes in routine ($p=0.565$), awareness of impact of disease ($p=0.273$), and awareness of functional status as a whole ($p=0.416$). The moderate dementia group had significantly PFAQ scores ($p=0.004$), lower MMSE ($p<0.001$), and a longer duration since the initial dementia diagnosis ($p=0.004$) compared to mild dementia participants.

DISCUSSION

This study demonstrated that people with both mild and moderate AD are able to communicate their experiences with progressing dementia and corresponding functional deficits. The analysis of the interview data indicates that the presence of impairments on awareness of the disease and of functional deficits is noticeable, even in the mild stages of AD. These impairments in awareness become worse over time as participants progress from mild to moderate AD. Although the relationship between awareness and disease severity is well known [30, 31], qualitative studies have demonstrated that people with AD are still able to describe their situations, needs, and experiences in everyday life across all dementia severity levels [32, 33].

Awareness of the disease seemed to be easier recognized than the awareness of specific functional deficits for participants with both mild and moderate AD, possibly because the recognition of impairments caused by the disease was expressed as a general con-

dition. Conversely, deficits in functionality may be more difficult to recall and identify because this level of awareness requires more objective and specific memories and judgments related to the complexity of particular tasks. A possible explanation related to the difficulties in recognizing functional deficits may be due to AD-related memory impairments, such as recent difficulties with functional tasks that could contribute to their awareness of these deficits [1, 21]. This might be particularly true for more complex ADLs.

The majority of the participants with mild AD manifested partially impaired awareness of functional deficits, but it was difficult for them to relate their functional decline to their cognitive impairment.

These results also showed that impaired awareness of disease and of functional deficits were manifested by distinct features. Across patients with mild and moderate AD, the impaired awareness of disease was characterized by more global perceptions, whereas the impaired awareness of functional deficits was evident through difficulties in describing specific examples of their changes in functionality. Several essential functional abilities were not even mentioned most responses, as participants in both groups were unable to describe more than two types of ADLs affected by their condition. Almost half of the moderate participants did not detail any ADLs that were affected by their disease. The mild group were slightly more successful than the moderate group in describing some changes related to ADL functioning. However, the comparison between self-report and scores on the PFAQ was more consistent in the moderate group than the mild group. A possible interpretation is that the people with mild AD overestimate their performance in ADLs because they tend to be more threatened by how these impairments might impact their autonomy [34]. No significant differences were observed with regard to some functional domains of awareness. Despite the fact that

the participants with moderate impairment were more cognitively impaired, both groups reports were similar concerning awareness of changes in routine, impact of the disease, and functional deficits as a whole. In general, both groups were not able to describe more than two changes in routine and also mentioned few functional impacts of the disease. These two domains had a major influence on the results. The interpretation of awareness of functional deficits as a whole are strongly underpinned by these two domains, because help for general and hygiene tasks were not often detailed by participants. Participants with mild dementia were significantly more unaware of their need for help to perform general tasks and for hygiene tasks compared to moderate dementia. This finding might be related to how patients with moderate AD require more assistance with ADLs due to their more advanced cognitive impairment. These more impaired individuals' daily experiences of requiring assistance might provoke frequent reminders and ultimately increase their awareness of deficits. Manifestation of awareness of disease and the recognition of memory deficits were similar in both groups, with awareness or partial awareness for most participants in both groups. However, it should be underscored that participants were asked about their memory whenever they could not remember it immediately.

The changes in ADL functioning mentioned by mild AD participants included: leaving the stove on, not going out alone, being monitored on the telephone by a family member, managing finances, sexuality, helping with house tasks, shopping, and taking a shower. The moderate AD group recognized changes in ADL in the following aspects: working, cooking, needing supervision during hygiene tasks, needing help with medications, and not being able to remember what to buy. Changes in instrumental ADLs were more readily recognized by participants in both groups than basic ADLs. This pattern suggesting a loss of instrumental before basic ADLs is in line with some studies that have proposed hierarchical models of ADL functioning [1, 6, 9].

One study suggested that people with dementia are capable of describing how dementia affected themselves and their lives [35]. Significant experiences included initial signs, coping efforts, concealing diagnosis, social withdrawal, existential anxiety, and the revival of the self [35]. Our study indicated that loss of awareness of basic activities occurs in more severe stages of the disease, when it is difficult for patients to acknowledge changes in general. With regard

to functionality, some questions were better understood and, consequently, more properly answered by participants. For example, questions related to the acknowledgement of the disease (1), to changes in ADL (2), and to the impact of the disease in life (3) elicited more accurate responses than questions regarding their need for help (4) and help with hygiene tasks (5).

Both groups of participants generally recognized memory impairments, changes in routine, and/or impacts in life, but almost all participants could not acknowledge the need for help and supervision on basic ADLs. The discrepancies between the answers, namely the recognition of the deficit but the lack of acknowledgement of need for help, may indicate the incapacity of the participants in properly recognizing the consequences of deficits in ADL. One study [36] found that even when people with AD manifest an awareness of the disease, they are still not able to realize the practical implications of their deficits. Another study [37] supported this result, finding that a large proportion of people with mild to moderate dementia did not perceive their memory loss as considerably impacting their daily routines. A possible explanation is that the ability to integrate current experiences with prior functioning may be hindered due to AD-related episodic memory impairment [38].

Our findings are consistent with other studies demonstrating that unawareness in people with AD is mainly manifested by poor recognition of changes in ADL functioning rather than an unawareness of the disease itself [14, 30, 31, 39, 40]. Awareness is a relational concept, always expressed in relation to an "object" of awareness assessment [17]. Thus, different objects will determine different kinds of judgments and levels of awareness, some of which are qualitatively different (e.g., the distinction between awareness of disease and functional status, as demonstrated in our findings). This qualitative difference may have resulted in participants judging the severity of their functional deficits in an inaccurate way, perhaps because the perception of functional deficits is more complex than the general understanding of having a disease [23].

Considering the reasonable accuracy of people with early stage dementia to estimate their own functional status, self-ratings of instrumental ADLs may be a valuable complement to the use of proxy ratings in clinical settings. This method could be especially valuable because since caregivers' ratings may be influenced by other factors such as stress [43]. Relevant information may emerge from collecting

information from both the patients with AD and their caregivers.

Strengths and limitations

To the best of our knowledge, this is the first qualitative study assessing self-report about their functional deficits in patients with AD dementia. The reports provided by the participants demonstrates their experiences, feelings and difficulties related to their awareness of the disease and corresponding functional deficits. The stage of the dementia influenced the narratives given by people with mild and moderate AD, showing the differences in the ability of recognizing changes in their routines. These findings may contribute to a better understanding of how to manage functional limitations in patient with AD. However, this study has some important limitations. The semi-structured interview format limited the scope of the types of ADLs that were surveyed. Utilizing an interview formal with more types of ADLs could provide more information concerning specific deficits in the awareness of functional status. In addition, this is a qualitative study and the findings represent only the participants who were included in this study. The findings cannot necessarily be generalized to others with AD.

Conclusion

Awareness of disease and awareness of functional status manifests with different degrees of complexity. We observed that the disease may be easier for patients to recognize and acknowledge than impairments in functional status in mild and moderate AD. The results of this study demonstrate that people with AD may express paradoxical intents to provide reports about functionality independent from dementia severity. That is, despite their ability to answer the questions, it is possible that attempts to hide deficits occurred in order to protect their autonomy. Further, the co-occurring presence of cognitive impairment may interfere with the ability to accurately identify and describe the full spectrum of functional limitations. However, our findings highlight that most people with mild and moderate AD can provide reports of at least some of their experiences of the impact of the disease in their daily routines and overall functioning. Therefore, our study contributes to help professionals and caregivers in developing strategies for coping with the difficulties in ADLs experienced by people with AD.

ACKNOWLEDGMENTS

Marcia Cristina Nascimento Dourado is researcher 2 funded by CNPq. Paula Gasparini Emery Trindade is researcher funded by CAPES. The authors would like to thank Michael A. Sugarman, for language editing assistance during the revision of the manuscript.

CONFLICT OF INTEREST

The authors have no conflict of interest to report.

REFERENCES

- [1] Mograbi DC, Morris RG, Fichman HC, Faria CA, Sanchez MA, Ribeiro PCC, Lourenço RA (2017) The impact of dementia, depression and awareness on activities of daily living in a sample from a middle-income country. *Int J Geriatr Psychiatry* **33**, 807-813.
- [2] Sousa RM, Ferri CP, Acosta D, Albanese E, Guerra M, Huang Y, Jacob KS, Jotheeswaran AT, Rodriguez JLL, Pichardo GR, Rodriguez MC, Salas A, Sosa AL, Williams J, Zuniga T, Prince M (2009) Contribution of chronic diseases to disability in elderly people in countries with low and middle incomes: A 10/66 Dementia Research Group population-based survey. *Lancet* **374**, 1821-1830.
- [3] Sousa RM, Dewey ME, Acosta D, Jotheeswaran AT, Castro-Costa E, Ferri CP, Guerra M, Huang Y, Jacob KS, Pichardo JGR, Ramírez NG, Rodriguez JL, Rodriguez MC, Salas A, Sosa AL, Williams J, Prince MJ (2010) Measuring disability across cultures—the psychometric properties of the WHO-DAS II in older people from seven low- and middle-income countries. The 10/66 Dementia Research Group population-based survey. *Int J Methods Psychiatr Res* **19**, 1-17.
- [4] Takechi H, Kokuryu A, Kubota T, Yamada H (2012) Relative preservation of advanced activities in daily living among patients with mild-to-moderate dementia in the community and overview of support provided by family caregivers. *Int J Alzheimers Dis* **2012**, 1-7.
- [5] Dias EG, de Andrade FB, Duarte YAO, Santos JLF, Lebrão ML (2015) Advanced activities of daily living and incidence of cognitive decline in the elderly: The SABE Study. *Cad Saúde Pública* **31**, 1-13.
- [6] Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW (1963) Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *JAMA* **185**, 914-919.
- [7] Martyr A, Nelis SM, Quinn C, Rusted JM, Morris RG, Clare L and on behalf of the IDEAL programme team (2019) The relationship between perceived functional difficulties and the ability to live well with mild-to-moderate dementia: Findings from the IDEAL programme. *Int J Geriatr Psychiatry* **34**, 1251-1261.
- [8] Mlinac ME, Feng MC (2016) Assessment of activities of daily living, self-care, and independence. *Arch Clin Neuropsychol* **31**, 506-516.
- [9] Njegovan V, Hing MM, Mitchel SL, Molnar FJ (2001) The hierarchy of functional loss associated with cognitive decline in older persons. *J Gerontol A Biol Sci Med Sci* **56**, M638-M643.

- [10] Clare L (2004) The construction of awareness in early-stage Alzheimer's disease: A review of concepts and models. *Br J Clin Psychol* **43**, 155-175.
- [11] Starkstein SE, Jorge R, Mizrahi R, Robinson RG (2006) A diagnostic formulation for anosognosia in Alzheimer's disease. *J Neurol Neurosurg Psychiatry* **77**, 719-725.
- [12] Lacerda IB, Souza MFB, Santos RL, Nogueira MML, Dourado MCN (2016) Concepts and objects of awareness in Alzheimer's disease: An updated systematic review. *J Bras Psiquiatr* **65**, 99-109.
- [13] Starkstein SE, Jorge R, Mizrahi R, Adrian J, Robinson RG (2007) Insight and danger in Alzheimer's disease. *Eur J Neurol* **14**, 455-460.
- [14] Dourado MCN, Laks J, Mograbi D (2016) Functional status predicts awareness in late-onset but not in early-onset Alzheimer disease. *J Geriatr Psychiatry Neurol* **29**, 313-319.
- [15] Maki Y, Amari M, Yamaguchi T, Nakaaki S, Yamaguchi H (2012) Anosognosia: Patients' distress and self-awareness of deficits in Alzheimer's disease. *Am J Alzheimers Dis Other Dement* **27**, 339-345.
- [16] Okonkwo OC, Griffith HR, Vance DE, Marson DC, Ball KK, Wadley VG (2009) Awareness of functional difficulties in mild cognitive impairment: A multi-domain assessment approach. *J Am Geriatr Soc* **57**, 978-984.
- [17] Marková IS, Clare L, Whitaker CJ, Roth I, Nelis SM, Matyr A, Roberts JL, Woods RT, Morris R (2014) Phenomena of awareness in dementia: Heterogeneity and its implications. *Conscious Cogn* **25**, 17-26.
- [18] Lacerda IB, Santos RL, Neto JPS Dourado MCN (2017) Factors related to different objects of awareness in Alzheimer disease. *Alzheimer Dis Assoc Disord* **31**, 335-342.
- [19] Nazlidou El, Moraitou D, Natsopoulos D, Papanitiou G (2015) Social cognition in adults: The role of cognitive control. *Hell J Nucl Med Supplement* **1**, 109-121.
- [20] Matyr A, Clare L, (2017) Awareness of functional ability in people with early-stage dementia. *Int J Geriatr Psychiatry* **33**, 31-38.
- [21] Dourado MC, Marinho V, Soares C, Engelhardt E, Laks J (2007) Awareness of disease in dementia: Development of a multidimensional rating scale. *Dement Neuropsychol* **1**, 74-80.
- [22] Dourado MC, Mograbi DC, Santos RL, Souza MF, Nogueira ML, Belfort T, Landeira Fernandez J, Laks J (2014) Awareness of disease in dementia: Factor structure of the assessment scale of psychosocial impact of the diagnosis of dementia. *J Alzheimers Dis* **41**, 947-956.
- [23] Trindade PGE, Santos RL, Lacerda IB, Johannessen A, Nascimento Dourado MC (2018) Awareness of disease in Alzheimer's disease: What do patients realize about their own condition? *Aging Ment Health* **23**, 1-8.
- [24] American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V)*. American Psychiatric Association, Arlington, VA.
- [25] Maia AL, Godinho C, Ferreira ED, Almeida V, Schuh A, Kaye J, Chaves MLF (2006) Application of the Brazilian version of the CDR scale in samples of dementia patients. *Arq Neuropsiquiatr* **64**, 485-489.
- [26] Bertolucci PH, Brucki SM, Campacci SR, Juliano Y (1994) O Mini-exame do estado mental em uma população geral: Impacto da escolaridade. *Arq Neuropsiquiatr* **52**, 1-7.
- [27] Dutra MC, Ribeiro RS, Pinheiro SB, Melo GF, Carvalho GA (2015) Accuracy and reliability of the Pfeffer Questionnaire for the Brazilian elderly population. *Dement Neuropsychol* **9**, 176-183.
- [28] Assis L de O, de Paula JJ, Assis MG, de Moraes EN, Malloy-Diniz LF (2014) Psychometric properties of the Brazilian version of Pfeffer's Functional Activities Questionnaire. *Front Aging Neurosci* **6**, 255.
- [29] Corbin J, Strauss A (2008) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, third edition. Sage Publications, Thousand Oaks, CA.
- [30] Dourado M, Laks J, Rocha M, Soares C, Leibing A, Engelhardt E (2005) Awareness of disease in dementia: Preliminary results in patients with mild and moderate Alzheimer's disease. *Arq Neuropsiquiatr* **63**, 114-118.
- [31] Souza MFB, Santos RL, Nogueira ML, Belfort T, Rosa RDL, Torres B, Simões P, Mograbi DC, Laks J, Dourado MCN (2015) Awareness of disease is different for cognitive and functional aspects in mild Alzheimer's disease: A one-year observation study. *J Alzheimers Dis* **43**, 905-913.
- [32] Thorsen K, Dourado MCN, Johannessen A (2018) Developing dementia: The existential experience of the quality of life with young-onset dementia - A longitudinal case study. *Dementia (London)* **19**, 878-893.
- [33] Johannessen A, Engedal K, Haugen PK, Dourado MC, Thorsen K (2019) Coping with transitions in life: A four-year longitudinal narrative study of single younger people with dementia. *J Multidiscip Healthc* **12**, 479-492.
- [34] Clare L (2003) Managing threats to self: Awareness in early stage Alzheimer's disease. *Soc Sci Med* **57**, 1017-1029.
- [35] Johannessen A, Engedal K, Haugen PK, Dourado MCN, Thorsen K (2018) "To be, or not to be": Experiencing deterioration among people with young-onset dementia living alone. *Int J Qual Stud Health Well-being* **13**, 1490620.
- [36] Mårdh S, Karlsson T, Marcusson J (2013) Aspects of awareness in patients with Alzheimer's disease. *Int Psychogeriatr* **25**, 1167-1179.
- [37] Powers SM, Dawson NT, Krestar ML, Yarry SJ, Judge KS (2016) 'I wish they would remember that I forget': The effects of memory loss on the lives of individuals with mild-to-moderate dementia. *Dementia* **15**, 1053-1067.
- [38] Mograbi DC, Brown RG, Morris RG (2009) Anosognosia in Alzheimer's disease - The petrified self. *Conscious Cogn* **18**, 989-1003.
- [39] Clare L, Nelis SM, Matyr A, Whitaker CJ, Marková IS, Roth I, Woods RT, Morris RG (2012) Longitudinal trajectories of awareness in early-stage dementia. *Alzheimer Dis Assoc Disord* **26**, 140-147.
- [40] Lacerda IB, Santos RL, Belfort T, Neto JPS, Dourado MCN (2018) Patterns of discrepancies in different objects of awareness in mild and moderate Alzheimer's disease. *Aging Ment Health* **26**, 1-8.
- [41] Matyr A, Nelis SM, Clare L (2014) Predictors of perceived functional ability in early-stage dementia: Self-ratings, informant ratings and discrepancy scores. *Int J Geriatr Psychiatry* **29**, 852-862.