What it is like to be an older person with memory complaints: the perception of women seen at a Physical Rehabilitation Center

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Abstract

Objective: To understand what it is like to be an older person with memory complaints from the perspective of women seen at a Physical Rehabilitation Center. *Method:* A qualitative exploratory descriptive study was conducted involving a population of older women aged >60 years who had impaired cognitive function, as measured by the Mini-Mental State Examination (MMSE), and subjective memory complaints was carried out. A questionnaire was applied to characterize the participants and an audio-recorded semi-structured interview based on a guiding question was conducted. The transcribed interviews were analyzed using Bardin's Content Analysis. *Results:* The age of the 19 participants ranged from 62 to 84 years, with mean of 72.37 (±6.72) years. Reading and analysis of the discourse produced in response to the guiding question revealed two categories: (1) feelings the older women experienced due to memory complaints; (2) daily life situations affected by memory complaints. *Conclusion:* Being an older woman with memory complaints was reported as challenging, promoting changes in daily life, impacting situations that used to be routine, and requiring readjustments both for the older individual with memory impairment and those around them.

Keywords: Memory loss. Elderly. Cognitive Dysfunction.

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INTRODUCTION

Memory can be defined as the ability to acquire, store and retrieve information and experiences. This is a complex cognitive process which is fundamental for learning, adaptation and survival as humans, allowing Information to be held in the mind for long periods and retrieved when needed[1]. At all times, this cognitive resource is used to perform daily activities and is a factor influencing Independence in everyday life[2].

Memory is one of the most impacted cognitive functions during aging. Aging is accompanied by decline in processing speed, attention span, episodic recall ability and execution of different tasks[3-5]. Memory complaints in older individuals are more prevalent among women[6,7].

Subjective memory loss or complaints in older people may be associated with objective dysfunction of memory loss and cognitive deficit, problems which can be revealed using specific tests[8].

The Mini-Mental State Exam (MMSE) is the most widely-used tool for screening cognitive status in adults and older people in Brazil and worldwide. Studies involving memory training apply the MMSE to assess and check change among individuals presenting this impairment, despite the fact this tool evaluates more than memory impairment[2] .

Aging can negatively impact quality of life of older people, especially when associated with memory complaints and cognitive decline. These factors directly affect autonomy, self-care, social interaction and functioning. Older people with these impairments and experiences may present depression, anxiety, irritability, aggressiveness, apathy, hopelessness, anguish and fear[2].

In the context of the COVID-19 pandemic, neurological symptoms were observed, including cognitive and mental impairment, during acute episodes of the disease and over the long-term. Of the different cognitive symptoms displayed, memory complaints are the most common[9].

Older age, low educational level, presence of comorbidities, severe COVID-19 infection, need for Intensive Care Unit (ICU) admission, and presence of *delirium* constitute risk factors for developing cognitive impairment over the long term[9].

Lockdown measures adopted to curb the COVID-19 pandemic promoted changes in everyday life, family and social relationships, as well as in the number of activities performed by older people. This change is associated with cognitive decline and impairment of functions such as memory and a worsening of cases of pre-existing memory problems[10].

The identification of memory complaints in older adults, and their objective assessment and monitoring of change, allows health professionals to plan and apply interventions to manage these issues, improving the independence and quality of life of individuals affected. In addition, this evaluation enables the adaptation and complementing of approaches employed for treating diseases affecting older people, toward better adherence and compliance with guidance, given these aspects are influenced by an individual´s capacity to process, retain and store information[2] .

The manner in which older people deal with experiences of loss during aging, including memory loss, is mediated by a number of different factors, such as culture, religiosity, social support, coping strategies and personal characteristics[11,12] .

Assessing the perceptions of older people regarding the impact of this impairment on their daily lives is important for professionals of heath teams. Knowledge of this perception can help inform professionals, allowing them to make their treatment strategies more individualized and humanized.

Previous studies show that gender differences exist in the way older individuals perceive their aging and the changes this process promotes[11]. Thus, the objective of the present study was to determine and understand what it is like to be an older person with memory complaints from the perspective of women seen at a Physical Rehabilitation Center.

METHOD

A descriptive qualitative exploratory study was conducted. The study population comprised older adults aged >60 years seen at a Physical Rehabilitation Center of a public university in Paraná state between February and August 2021 who had cognitive dysfunction, as confirmed by the MMSE and reports of subjective memory complaints. Exclusion criteria were: being male, history of COVID-19 infection, diagnosis of diseases whose clinical symptoms precluded verbal communication; being bedridden (dependents); and having physical disability.

Participants were contacted by telephone to schedule the first stage of data collection. At the first face-to-face meeting (held in room at rehabilitation center), a questionnaire collecting the following sociodemographic variables on participants was applied: name, age, sex, marital status, living arrangement (alone or with others), job, family income, education and religion. These variables were analyzed using simple descriptive statistics.

The MMSE was used to objectively screen older women who had subjective memory complaints. When applying the MMSE, educational level is a factor influencing the scores obtained[13]. The cut-off points established by BRUCKI et al.[14] were adopted to determine the presence of cognitive impairment: 20 points for illiterate subjects; 25 for 1-4 years of education; 26.5 for 5-8 years; 28 for 9-11 years; and 29 for >11 years of formal education. In the group of individuals whose score indicated cognitive deficit, a second telephone call was made to notify them of the results and check for the presence of subjective memory complaints or otherwise. Participants who reported this complaint were invited to return for a second face-to-face meeting to undergo a sound-recorded semi-structured interview based around the following guiding question: "For you, what is it like to be an older person with memory complaints?".

Interviews were sound recorded, transcribed in full and labeled with an identifier beginning with the letter E followed by numbers (denoting randomly assigned order in which interviews were conducted) for Content Analysis[15].

During both the first and second interviews with participants, the sanitary health measures implemented by the rehabilitation center were observed in order to prevent contact with and spread of the coronavirus. These measures were necessary because data collection took place in 2021, a period in which the provision of health services was resuming amid the pandemic.

The researchers tasked with data collection, as well as study participants, underwent screening checks for signs and symptoms of COVID-19 prior to admission to the center. Also, while on the premises, the use of alcohol cleansing gel (70%) to sterilize hands was compulsory, and of alcohol fluid (70%) for cleaning desks and chairs, in additional to wearing of face masks and respiratory precautionary measures.

Distancing of 2 meters between researchers and study participants was maintained in the data collection room, and windows and doors kept open to ensure ventilation of the space, while assuring privacy when collecting the necessary information.

The present study was approved by the Ethics Committee for Research involving Humans at the University Teaching Institution of which the center was part, under permit no. 3.990.370, in accordance with Resolution nos. 466/2012 and 510/2016. All participants had read and signed the Free and Informed Consent Form prior to application of the questionnaire.

RESULTS

A total of 79 older adults were treated at the center between February and August, 2021. This patient group comprised 58 (73.42%) women and 21 (26.58%) men. All 58 female patients were included in the study, of which 20 (34.48%) had cognitive dysfunction, as determined by the MMSE.

These 20 individuals reported memory complaints, however, 1 patient refused to take part in the semi-structured interview for personal reasons. Thus, for the remaining 19 women interviewed, age range was 62-84 years and mean age was 72.37 (±6.72) years. With regard to performance on the MMSE, mean score was 9.58 (±4.02) points. Participant characteristics are presented in Table 1.

Table 1. Characteristics of study participants (N=19), Cascavel, Parana, 2021.

Variables	n (%)
Marital status	
Married	9 (47.37)
Widow	7 (36.84)
Single	3 (15.79)
Employment status	
Retired	17 (89.47)
Housewife	2 (10.53)
Monthly family income (minimum wages)	
≤1	8 (42.11)
1-2	3 (15.78)
3-5	8 (42.11)
Education	
Illiterate	3 (15.79)
Primary incomplete	3 (15.79)
Primary complete	6 (31.58)
Secondary incomplete	1 (5.26)
Secondary complete	2 (10.53)
Higher incomplete	2 (10.53)
Higher complete	1 (5.26)
Post-graduate complete	1 (5.26)
Religion	
Catholic	14 (73.68)
Evangelical/Protestant	5 (26.32)

Source: Created by authors, 2021.

Reading and analysis of answers given verbally in response to the guiding questions revealed the following categories: a) feelings experienced by participants due to memory complaints; b) everyday situations impacted by memory complaints.

Feelings experienced by participants due to memory complaints

The participants presenting memory complaints described this situation using negative adjectives such as "hard", "bad", "awful", and "sad".

> "It´s the worst thing ever, because I always was, I always had a sharp memory [...]" (E14).

> "[...] it´s sad, I think there is nothing worse than someone whose "lost" their memory" (E18).

The results showed that the participants associated negative feelings with their memory problems. The individuals reported feelings of anger, distress, shame, discomfort and hopelessness. Positive feelings, such as joy, were reported when managing to remember something.

> "It maddens me you know, when I want to remember things but I´m unable to [..] after some hours I remember, which makes me really happy because I have managed to remember" (E8)

> "[...] it´s an issue we have sometimes, feelings of shame [....]" (E11).

> "It´s distressing, depressing" (E18).

> "[…] sometimes I mislay something, leave things in the wrong place in the kitchen [...], it´s annoying" (E3).

As a result of the memory complaints, participants felt dependent on others to do things they used to do alone, such as visiting the doctor or going out to run errands.

> "I think it's really terrible because you need, I think someone else, to accompany you the whole time, especially to go to the doctor, because they prescribe medications and the right time to take them, and we need to know this precisely" (E8).

> "Relying on others to walk together, I can´t walk alone" (E11).

Fear featured in the everyday lives of the women with memory complaints. The participants reported being fearful over their clinical memory problem worsening, fear of facing the future alone with declining memory, fear of early onset of more severe memory issues and also of becoming dependent on others.

> "I´m fearful that one day I, as they say, totally lose it [...]. [...] I´m afraid of not remembering anything [...]" (E5).

> "[...] at the moment, we, despite being a bit forgetful, we are lucid enough to go out, deal with things, but its tough girl, imagine later on in the future how it´s going to be, a few years from now" (E8)

> "My only worry is that I think maybe mine is coming a bit earlier, because I am 66 years old" (E4).

Some of the participants appeared to have accepted their memory issue, believing this is a normal part of aging.

> "[...] I know this is natural, I understand it´s normal for my age" (E10).

> "I accept it, I kind of accept it, because it's physiological this, there´s no getting away from it, it's physiological and I know this is coming, you see" (E4).

Everyday situations impacted by memory complaints

During the interviews, the participants spoke about the severity and frequency with which memory problems arise in their daily lives.

> "Actually, I forget everything" (E2).

> "I forget a lot of stuff" (E1)

> "It´s not very common, sometimes I have whole days without problems, remembering everything" (E19).

Forgetting where they had "put" something was a recurrent theme in the narrative of the study participants.

> "[...] I put things somewhere else and then forget I´ve done it you know, [...]" (E14).

> "Sometimes I already have the thing I´m looking for but no, I go hunting for it, then come back and there it was" (E11).

> "I´m forgetful, sometimes I want to fetch something, go to get it and start wondering, what is it I´m getting, then I return, walk around a bit, and then I remember" (E17).

> "Sometimes I grab my handbag [...] put it away and then forget where I put it" (E19).

Interviewees reported not being able to recall whether they had done what they had to do. They reported often "mixing" multiple tasks, while doing one, they start another, forgetting what they were doing in the first place.

> "Sometimes we go out thinking we have done that, and have not done it, so we get back and shortly afterwards we remember, maybe [...]" (E3).

> "There are times when I get a pressure device and check my pressure, finish that and then start cleaning the house, then I mix it, I want to do everything at once and lose track of what I´m doing" (E7).

In some cases, the participants forgot things while cooking, preparing a meal and forgetting what they were doing, needing to maintain full concentration in order to complete the task,

> "I put the rice on, if I leave it for a moment, turn to the sink, I forget the rice, because my stove is behind me, and turn to the sink to do something, and don't remember the rice any more" (E2).

> "If I move away, I forget it and it burns, I can´t move away, I need to pay attention to it you know, like that" (E7).

The relationship of the women with others was affected by the memory difficulty, not recalling what was said, saying things they never used to verbalize, forgetting people´s names and details conveyed to them. This problem had led some people to stop talking to them.

> "[...] say something, arrange something with somebody and then no longer remember [...], nobody talks to me anymore because they know I'm losing it [...]. [...] I no longer know anyone´s name, I need to read the name or write it down, really bad [...]" (E14).

> "Sometimes I even forget names of family members you know, my mind goes blank, it vanishes [...]" (E8).

> "Saying things which, sometimes shouldn't be said" (E11)

The interviewees stated that they had experienced situations in which they encountered difficulties to locating/recognizing where they were, even in familiar places; and situations where, having gone out, they forgot why they had left home.

> "Memory loss is like that, there are times when we don´t know where we are" (E7).

> "You go someplace, reach the street, get there and don´t know why you went, go back home" (E2).

> "You go into town to a place and don´t go in, visiting another store instead, you wanted to go in this one and not that one" (E11).

> "There were occasions when I got the bus, I had to think where I was supposed to get off, I didn´t remember, it´s awful" (E7).

The participants reported missing appointments, such as visits to the doctor, and not recalling whether they had taken their medication or not, or taken them at the right time.

> "I forgot my appointment on the 1st that I had scheduled in order to update my prescription, I forgot, nobody reminded me and I ended up forgetting" (E7).

> "Yes, the medications sometimes as well, I also miss the time, not by a lot, but it happens [...]. [...] On occasions I take it and then I´m left wondering, did I take that one, at that time?" (E3).

DISCUSSION

This analysis of the narrative content of the study participants revealed that being an older woman with memory complaints was associated with negative feelings and impacts on situations of daily life due to this deficit. Having memory complaints was reported as being "bad", "sad", "hard", "unpleasant" and "unwanted", which in turn promoted feelings of anger, distress, shame, embarrassment, hopelessness and fear.

Activities of daily living, ranging from more basic (everyday tasks) to more complex (planning a trip, driving, engaging in sports, taking part in community groups, etc.), can be impacted by memory complaints. This can give rise to depressive symptoms due to loss of the ability to perform tasks that were hitherto possible[16].

Overall performance of the individual on these activities is closely linked to the integrity of their intellectual functioning. When older people exhibit poor cognitive performance, symptoms such as distress, rage, blame and embarrassment can emerge[17].

Older individuals presenting subjective memory complaints are more prone to having low self-esteem, stress and depressive symptoms than their counterparts without these problems[18]. During

the first two years of onset of memory problems, depressive symptoms tend to be worse and more evident. In other cases, cognitive memory decline causes reduced functioning and self-care, resulting in depressive signs and symptoms[19].

With advancing age, loss of autonomy becomes a key factor contributing to reductions in well-being and quality of life. When this loss is associated with functional and cognitive decline, the impact on quality of life is compounded[20].

Fear over cognitive decline and its consequences may stem from previous experiences of memory issues seen in other people[21]. Exposure to this situation triggers apprehension regarding the future, since many individuals in this age group experience rapid decline, limitations in activities of daily living and end up becoming dependent on others[22]. Older people with impaired memory tend to hold a pessimistic view of the future, because of the possibility of developing dementia[23].

In older age, women tend to spend the vast majority of their time within the home, engaging in household tasks such as cooking, cleaning and tidying up[24]. Family caregivers of older people with memory problems report that the elders put themselves in danger involving situations such as lighting the gas stove and forgetting to turn it off and handling saucepans on the hotplate.

Symptoms of cognitive decline can include problems remembering names, word-finding difficulties when trying to describe something, and mislaying objects[6].

Older people often have chronic diseases which require pharmacological treatment. When this population has memory issues, they may forget whether they have already taken their medications or have difficulty adhering to the prescribed timing[27].

Strategies adopted to counter these problems include associating the time of administering drugs with a meal for example, or by using reminder notes in the event of episodes of forgetfulness. This scenario may pose a health risk in promoting poor treatment adherence and quality, as well as complications secondary to lack of self-care[28].

Many older individuals with memory complaints do not seek treatment, holding the misconception that memory problems are part of the "normal" aging process. Other individuals see a stigma attached to memory impairment, construing this as a problem which must be concealed from family and the people around them[29].

Having a more active brain can help prevent, slow or attenuate the factors associated with cognitive aging, such as memory decline. Interventions with beneficial outcomes have been recommended, proving positive for health of older people by improving performance on activities of daily living[30].

Cognitive training entails interventions applied to stimulate thinking and cognition with different degrees of difficulty and intensity. The objectives of training include maintaining or improving cognitive and functional capacity for activities of daily living. These typically involve standardized structured tasks for training abilities such as attention, memory, information processing speed and problem-solving[30]. These programs can be applied alone by a health professional or in a multi-disciplinary fashion including professionals from different areas[31].

Cognitive training using an abacus, an apparatus which stimulates attention and reasoning, is a fun strategy for optimizing cognitive reserve of older individuals, boosting memory[30]. Other strategies can be used, such as memory games, memorizing drawings, differentiating colors, explaining meanings of common expressions, writing shopping lists or spotting the maximum items in a room, logic and language exercises, such as reading a text with numbers simulating letters, texts containing shuffled letters, reading a word backwards, writing own name or drawing with the non-dominant hand[32].

Formal and informal support groups are forums of social interaction that potentialize the competences of older people, helping them to play their role in society, overcome difficulties and change attitudes amid health-disease[33].

With regard to intellectual and psychological aspects, informal and formal groups prove important in promoting reflection on changes which occur during this stage of life. The fact that older people

can vent their feelings, feel embraced and heard, awakens dormant potential and fosters self-esteem, warding off isolation and loneliness, improving self-care, as well as relationship with family members[16,33].

Regularly screening the cognitive ability of older people for early detection and diagnosis of memory decline is an important measure toward prevention and early treatment of memory complaints[2].

In the present study, the data collection was performed in 2021, limiting the number of women included. During this period, the number of individuals undergoing treatment at the study venue was lower relative to the pre-pandemic period. Many subjects, when invited to visit the health service where the study was run, turned down the assessment and treatment for fear of leaving home and getting infected by the coronavirus.

In addition, lack of contact with people, change in routine and reduced level of daily functional activities during the lockdown amid the COVID-19 pandemic have been associated with poorer concentration and memory loss[10], possibly influencing the responses given.

Moreover, lockdowns may have had a negative impact on participants´ mental health, consequently influencing their experiences regarding memory complaints. People facing social restriction and deprivation can experience negative feelings and may exhibit stress-related symptoms, anxiety and depression, and also exacerbation of previous mental disorders[10,34]. The older population is a group deemed more susceptible to these phenomena when faced with this type of situation[35].

CONCLUSION

Being an older woman with memory complaints proved a challenge, impacting the daily life of participants, promoting changes in previously normal situations, requiring re-adaptation by both the patient and those around them.

Decline in memory was associated with experiencing negative feelings, dependence for tasks previously performed alone, and with attitudes of acceptance on the misconception that impairments were inherent to the natural physiological process of aging. The women reported starting tasks and not finishing them, encountering difficulties orienting themselves in familiar places, and noted deterioration in their interpersonal relationships. Participants also reported problems forgetting where they had put things, important dates, managing medications and health-related appointments.

Future studies should investigate what it is like to be an older man with memory complaints. Lastly, studies on the objective perception and evaluation of these complaints in older people, before and after applying cognitive training, and exploring their impact on memory deficits should be conducted.

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- Camila Costanaro: Writing - Review and Editing
- Vilmar Malacarne: Writing - Review and Editing
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