

Cognitive stimulation for older people with Alzheimer's disease performed by the caregiver

Estimulação cognitiva para idoso com Doença de Alzheimer realizada pelo cuidador
Estimulación cognitiva para mayor con Enfermedad de Alzheimer realizado por cuidador

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ABSTRACT

Objective: to learn the influence of cognitive therapy at home, conducted by the caregivers of older people with Alzheimer's Disease. **Method:** a case study was developed with five older people with Alzheimer's Disease and their caregivers. The stages of research development were: orientation with the caregivers; selection of older people and caregivers; approach of the study subjects at home; weekly meetings and reapplication of tests to follow up the cognitive function of the participants. **Results:** in three months it was possible to identify improved cognition, verified by the result of the Mini-Mental State Examination (MMSE). The scores of the other tests (KATZ, LAWTON, CLOCK TEST and VFT) remained the same. **Conclusion:** this strategy can be considered a light technology of nursing care for older people with dementia. When providing this care with the support of a nurse, caregivers re feel less anxious and understand the disease better.

Key words: Elderly; Dementia; Cognitive Therapy; Gerontological Nursing; Technology.

RESUMO

Objetivo: conhecer a influência da estimulação cognitiva no domicílio, realizada pelo cuidador de idosos com Doença de Alzheimer. **Método:** realizado estudo de caso com cinco idosos com Doença de Alzheimer e seus cuidadores. As etapas de desenvolvimento da pesquisa foram: orientação aos cuidadores, seleção dos idosos e cuidadores; abordagem dos sujeitos no domicílio, encontros semanais e reaplicação dos testes para acompanhamento da função cognitiva do idoso. **Resultados:** no período de três meses foi possível identificar melhora da cognição, verificada pelo resultado do Mini Exame do Estado Mental (MEEM). Os demais testes (KATZ, LAWTON, TDR e TFV) mantiveram os escores iniciais. **Conclusões:** esta estratégia pode ser considerada uma tecnologia leve do cuidado de enfermagem para idosos com demência. Quando o cuidador realiza este cuidado, após o suporte do enfermeiro, sente-se menos ansioso e com maior compreensão da doença.

Descritores: Idosos; Demência; Terapia Cognitiva; Enfermagem Gerontológica; Tecnologia.

RESUMEN

Objetivo: conocer la influencia de la terapia cognitiva en domicilio, llevada a cabo por cuidadores de ancianos con Enfermedad de Alzheimer. **Metodología:** llevado a cabo un estudio de caso de cinco ancianos con Alzheimer y sus cuidadores. Las etapas de desarrollo de la investigación fueron: orientación con los cuidadores, selección de los ancianos y cuidadores; abordaje de los sujetos em domicilio, encuentro semanales y reaplicación de los testes de la función cognitiva del anciano. **Resultados:** en los tres meses fue posible identificar la mejora de la cognición, verificada por el resultado de MMSE. Las otras pruebas mantienen las puntuaciones iniciales (KATZ, LAWTON, TDR y TFV). **Conclusión:** esta estrategia puede ser considerada como una tecnología leve del cuidado de enfermería para ancianos con demencia. Cuando el cuidador se dio cuenta de esta atención, tras el apoyo de la enfermera, se siente menos ansioso y más comprensión de la enfermedad.

Palabras clave: Ancianos; Demencia; Terapia Cognitiva; Enfermería Gerontológica; Tecnología.

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INTRODUCTION

This study addresses cognitive stimulation in older people with Alzheimer's disease, applied by trained caregivers and supervised by nurses. The objective was to learn the influence of this modality of cognitive stimulation as a homecare technology.

Alzheimer's disease (AD) is the most common dementia syndrome among the older population. It is characterized by multiple cognitive decline involving memory impairment and progressive loss of functional capacity⁽¹⁾. Nevertheless, recent studies have shown that non-pharmacological interventions, such as cognitive stimulation experienced by older people with AD have improved the performance and behavior in activities of daily living⁽²⁻³⁾.

This improvement is due to brain plasticity, which is the ability of the adult brain to adapt according to circumstances. In older patients with dementia, cognitive stimulation is intended to activate the existing functions so they can compensate for those that are compromised⁽⁴⁻⁵⁾.

Non-pharmacological approaches such as cognitive stimulation in seniors include: reality orientation therapy through the use of calendars, journals, videos, pictures of family members; reminiscence, in which they use past experiences of the patients; use of external supports, which involves training and use of instruments; learning without mistakes which consists in taking the patients to learn new information without making mistakes, helping them perform daily tasks, among others^(2,5).

These techniques, combined with drug treatment, can help stabilize or even result in slight improvement of cognitive and functional deficits. Authors also suggest that support and counseling interventions should be provided to families and caregivers in order to reduce the disorders among family members, promoting the well-being of the older people with relatives or caregivers^(2,5-6). Thus, in this study, caregivers are encouraged by nurses to develop and continue this care at home.

The theoretical framework of Merhy was used, which defines the concepts of Technology in Health Care, articulated with the concepts of Paterson and Zderad's Humanistic Theory, since the intention was to enhance the humanistic practice of care when inserting the caregiver as part of the assistance provided to older patients with dementia⁽⁷⁻⁸⁾.

This study is relevant with regard to the role of nurses and their integration into the multidisciplinary team, since it presents a technology that is poorly used by professionals who assist seniors with dementia and their caregivers. In addition, it provides instructions for the application of cognitive stimulation in older people by the caregiver at home. The objective was to learn the influence of cognitive stimulation at home, when performed by the caregiver of older people with Alzheimer's disease.

METHOD

A descriptive case study, using a qualitative approach, was carried out with five older adults and their caregivers who

attended the program entitled "Nursing in the Health Care of Older People and their Caregivers at Fluminense Federal University (EASIC/UFF)".

In this program, nursing has conducted several activities coordinated by the UFF faculty nurses, such as nursing visits to the older adults and their caregivers, guidance and informative lectures to these caregivers, therapeutic workshops with seniors with dementia, informative workshops and assistance to caregivers of older people with dementia and home visits.

Therapeutic workshops for older adults and activities of guidance and support to the caregivers of these seniors, occur once a week, lasting approximately two hours. Currently, 13 seniors and their caregivers participate in therapeutic workshops, characterizing a small population.

The inclusion criteria for the older adults were: having a probable diagnosis of Alzheimer's disease; compatible scores on the Mini-Mental State Examination (MMSE) to the cognitive deficits associated with mild and moderate dementia, according to their level of education; making use of medication for dementia; family or formal caregivers who were responsible for the main care of the seniors.

Exclusion criteria were: not attending the workshops at least twice a month; having their medication for dementia suspended during the study period; presenting the condition of cognitive deficits associated with depression, delirium and other psychiatric disorders or having symptoms compatible with dementia at an advanced stage; caregivers who cared for the seniors during a period of less than a month or had been replaced during the intervention period; caregivers unable to read and understand the activities proposed by the researchers.

After defining the inclusion and exclusion criteria, five seniors and their caregivers remained in the sample. Data collection occurred from July to October 2011, according to the steps below:

1) Guidance lecture to caregivers - held on the day and time of the workshop. The topics were: Understanding the dementia process, benefits and ways of carrying out cognitive stimulation in the home environment for older people with dementia. At the end of the lecture, each caregiver was briefed on the stages of the study and received a written instruction guide, prepared by the researchers as a reference source with information about dementia. On this day, the researchers scheduled the first meeting at the participant's residence to begin the cognitive stimulation activities.

2) Weekly meetings at home - lasting about one hour and thirty minutes to implement cognitive stimulation activities. At the first meeting, a form for the sociodemographic characterization of the older adults and their caregivers was applied. Then, the cognitive impairment of the senior was evaluated by applying the tests. Based on the collected data, cognitive stimulation activities were planned week by week according to the senior's specificities. Twelve meetings with each senior and caregiver were performed.

All tests used to assess the cognitive impairment of the older adults were validated and adapted to the Brazilian culture. These were:

- Mini-Mental State Examination (MMSE): Evaluates temporal and spatial orientation, learning and recall, attention and calculation, language, and visuospatial skills⁽⁹⁾.
- Katz scale (Katz): Evaluates the senior's performance in carrying out activities of daily living (bathing, dressing, toileting, transferring, continence and feeding)⁽¹⁰⁾.
- Lawton Scale (Lawton): Evaluates the functional performance of the senior in terms of instrumental activities that enables them to maintain an independent life⁽¹¹⁾.
- Clock Drawing Test (CDT): Checks visuospatial skills, executive functions, and memory by asking the subject to draw a clock⁽¹²⁾.
- Verbal Fluency Test (VFT): Evaluates semantic memory and phonetics by asking the senior to say, in one minute, the largest number possible of names from predefined groups (animals, fruits, flowers)⁽¹³⁾.

3) Assessment of the older adult and the actions of the caregiver after the introduction of cognitive stimulation activities - after the completion of the first battery of tests (pre-test), a reassessment of the senior at the end of each month was held within the study period (post-tests 1, 2 and 3).

The activity planning was carried out individually, based on the detection of deficiencies and daily limitations. The following resources were offered to caregivers: figures, object identification, calendar, clock, relationships with people, environment recognition, and encouragement to manual (knitting, crochet, sewing and embroidery), leisure (sports, games, hiking, dancing) and intellectual activities (reading books, newspapers and magazines).

Thus, attention, planning, reasoning, language, and other fields were developed. At each meeting, the researchers were available to answer questions and solve conflicts that occurred during the development of activities throughout the week. Study data were also collected through participant observation during the performance of cognitive stimulation activities.

All materials were analyzed and interpreted in the light of the theoretical and methodological framework covering the concepts of Technology in Health Care and the Humanistic Nursing Theory by Paterson and Zderad. Interventions and guidelines made by nurses were oriented according to Merhy who mentions that technology in health care should have the following elements: access, acceptance, bonding, and empowerment. Data analysis focused on Paterson and Zderad's humanization⁽⁷⁻⁸⁾.

The study was approved by the Research Ethics Committee of the Medical Sciences Center of UFF under Protocol 214/10 and all subjects (seniors and caregivers) signed a free and informed consent form.

In the presentation of the results, the seniors were identified by the letter S followed by a number, according to the order of the interview, to characterize the subjects (S1, S2, S3, S4 and S5). Caregivers were

identified by the letter C and the same number given to the senior they were responsible for (C1, C2, C3, C4 and C5).

RESULTS

Five seniors and their caregivers were interviewed. Most of the older adults were women⁽⁴⁾, aged over 71 years, who had 4 to 8 years of schooling (one of them with over 18 years of schooling), three of them were widowed and two were married, lived with one or more family members and only two received retirement benefits. All had dementia for five years or more and were taking other medications not associated with the disease, especially those used to treat systemic hypertension, a common disease in this age group.

Regarding the caregivers, most were also women and aged over 50 years. Among them, only one was a formal caregiver and the predominant degree of kinship was that of children of the older adults. As for their marital status, most were married. All had more than eight years of study and had other activities besides caring for the senior.

The results obtained from the assessments carried out before and after the application of cognitive stimulation activities at home were organized and presented through graphs.

Regarding the results obtained from the MMSE, it was observed that the scores of all seniors increased after the introduction of cognitive stimulation activities, which can be seen in the graph as of the post-test 1. Seniors S1, S3, S4, and S5 maintained the higher MMSE scores in relation to the pre-test (from post-test 1 to post-test 3). Senior S2 showed an increase in the MMSE from the pre-test to post-test 1, followed by a regression.

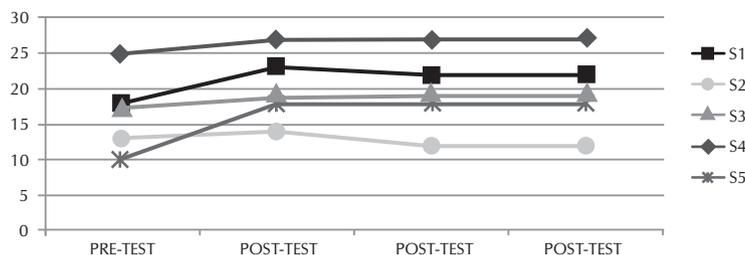


Figura 1 - Comparison between Mini-Mental State Examination scores before and during the implementation of cognitive stimulation activities at home, Niterói, 2011

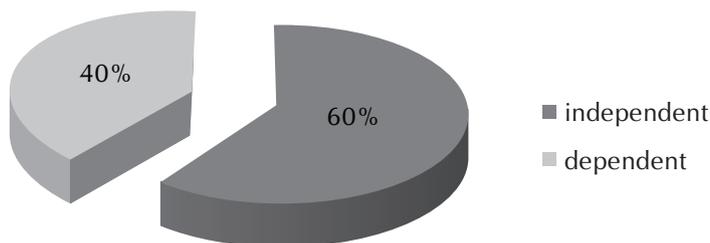


Figura 2 - Comparison between Katz scores before and during the implementation of cognitive stimulation activities at home, Niterói, 2011

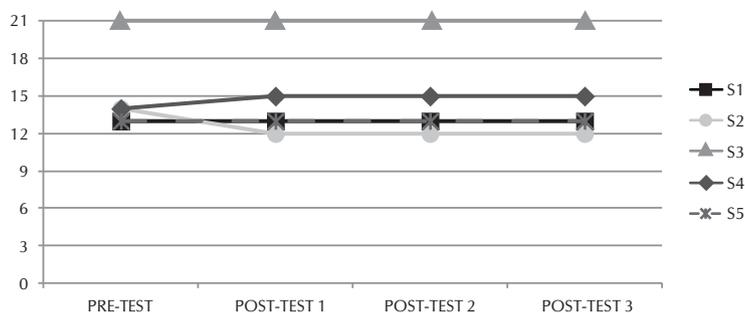


Figure 3 - Comparison between Lawton scores before and during the implementation of cognitive stimulation activities at home, Niterói, 2011

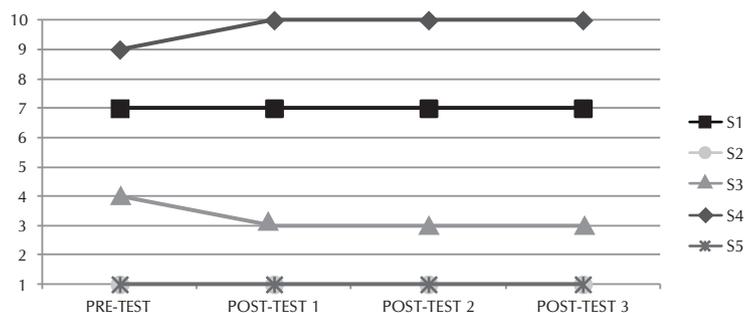


Figure 4 - Comparison between Clock Drawing Test scores before and during the implementation of cognitive stimulation activities at home, Niterói, 2011

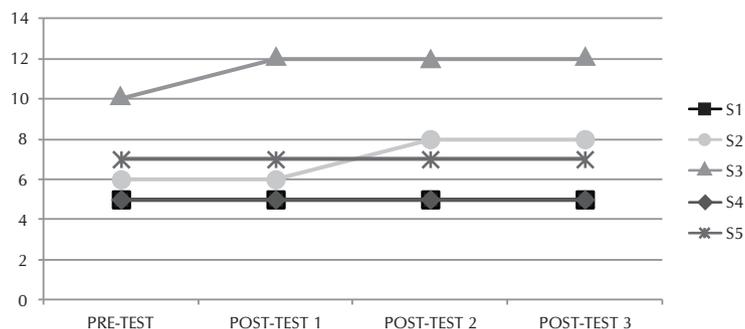


Figure 5 - Comparison between Verbal Fluency Test scores before and during the implementation of cognitive stimulation activities at home, Niterói, 2011

On the Katz scale (Figure 2), the score was constant for most seniors in carrying out activities in the household, 60% of the them have remained independent and 40% dependent. During the course of the stimulation activities, these seniors showed a decreased level of dependency, improving the performance of activities of daily living. This fact could not be identified through the scales, but through the words of caregivers, since the scale does not specify the degree of dependence of the senior in a particular activity, it only determines whether they are dependent or not for the activity.

In the Lawton scale (Figure 3), most older adults remained dependent, i.e., with scores below 21 points, which is

characteristic of a person with dementia. It was also possible to observe that the scores of three seniors increased during the implementation of the activity at home.

These data demonstrate that instrumental activities are more compromised within the studied group.

In the CDT, the education level did not influence the cognitive impairment of the older adults, as only one could draw the clock correctly marking the requested time, and he had only completed primary education. The others presented difficulties, two did not even manage to begin drawing the clock (S2 and S5) and only one subject who showed difficulties at the beginning drew the clock more completely during the research (S4).

The Verbal Fluency Test has shown different results for each of the seniors. The most affected ones have kept low scores throughout the entire study (S1 and S4). Amongst them, one had more than eight years of formal education (complete higher education).

Besides applying tests to assess cognitive functions, the implemented activities were supervised and monitored, and the caregivers' behaviors towards their feelings and expectations were observed with the aim of evaluating the influence of home-based cognitive stimulation, conducted daily by the caregivers of seniors with AD. By aligning the data collected, elements - which might, at times, become limiting or potential factors for the application of the strategy at home - were observed. These elements are described as follows.

Time availability

Before beginning each activity, the caregiver was instructed to stimulate the senior three days a week so that he/she would be more frequently stimulated because, as mentioned before, when stimulus happens continuously combined with the medical treatment, there is a greater likelihood to postpone or stabilize dementia symptoms. Despite that, even after instruction, it was observed that stimulation was executed at varied time periods.

Regarding the period of the day in which activities were conducted, caregivers respected the time when the senior felt more active and willing to accept the activity. This moment also depended on the caregiver's availability. This was already expected because most caregivers were housewives who took over the responsibility for the senior almost on their own.

Feeling of being lonely

Feelings of sadness, abandonment, loneliness, mood swings and irritability were always present among the caregivers in this study. The vast majority took advantage of the meeting time both to confess feelings - of sadness, lack of patience and abandonment by other family members - and to ask for psychological assistance.

All caregivers reported that the senior presented constant fluctuations in mood and behavior, besides disorientation and irritability. They also informed that, due to the senior's constant behavior oscillation, they also suffered changes in their habits and behavior, becoming irritable, stressed and presenting insomnia, besides being constantly tired.

The seniors' constant behavioral alterations had a very negative impact on the caregivers' lives, which made them more susceptible to events of depression and anxiety. Throughout the study, some caregivers were referred to the UFF Psychology service for assistance, since they presented the need for such support.

Lack of preparation

Lack of security and preparation to look after the seniors was reported by the caregivers themselves. Alzheimer's disease has a series of clinical manifestations, which can vary among individuals, thus emphasizing the importance of a nurse's close actions alongside the caregivers by offering them support, orientation and encouraging information exchange among them.

Caregivers' lack of preparation may also lead to their physical, emotional and mental strain. When they are deprived of information that can enhance their relationship, it becomes difficult for them to accept the disease and caregivers might be more instable and insecure, which can result in stress, mood swings and the impairment of their own health.

While administering the cognitive stimulation activities, it could be noticed that caregivers demonstrated less insecurity when they took action towards conducting the activities in a more dynamic and autonomous manner.

Caregivers' perception

Caregivers looking after older people have shown great interest in broadening their knowledge in AD, in being informed of other studies in the area and in other kinds of services both for the senior and for themselves.

It was also observed that despite having a short period of time available and the feeling of being alone in regard to the senior's care, besides the lack of preparation to deploy stimulation at first, after the research was conducted, there was an increase in the will to improve the care offered, by solving doubts about the different aspects involving the disease.

DISCUSSION

During the three months of follow-up with both seniors and caregivers, what has turned out to be even more remarkable, after the introduction of home-based cognitive stimulation activities, was the MMSE score increase. This is highly significant to older people with AD and demonstrates the relevance of encouraging stimulation practices in a continuous way, along with the caregivers' participation.

The cut-off points considered for the MMSE were the ones established in Brazilian studies: below 13 points for dementia, 13 points or higher for illiterate individuals, 18 points or higher for those with 5 or more years of formal education and 26 points for those with a college degree⁽⁹⁾.

It is known that the mean decrease per year in the MMSE score among older people with AD is approximately 3 points⁽⁹⁾. The length of time through which the study was conducted (three months) has precluded the possibility of using this parameter. However, with the introduction of the home-based activity, it was possible to observe a stabilization in the clinical pattern. This is prominent when it comes to a senior with a progressive cognitive impairment due to AD.

A fact that was particularly noteworthy was that all seniors showed a considerable increase in punctuation in the Temporal Orientation Test of the MMSE, after the implementation of the home-based stimulation activities. At the first tests carried out (pre-test), the seniors obtained low scores, since they had no recollection of the date, month, and year, claiming they had no habit of looking at the calendar. In fact, it was not about a lost ability, but an underused ability. After stimulation using a calendar and a watch and instructions to the caregiver on the importance of keeping the senior's temporal orientation, this domain showed a significant improvement.

Regarding the activities assessed by the Katz Index (bathing, dressing, toileting, transferring, continence and feeding), most of the seniors remained independent, which is confirmed by the data of other studies. According to these studies, there would be an orderly regression as a part of the ageing physiological process, in which functional losses would range from the most complex to the most basic functions, whilst the most basic and least complex functions could be retained for a longer period⁽¹⁰⁾.

The most basic functions are regarded as the ones performed every day, towards the necessities of the body, unlike the most complex activities, in which several abilities are required by the individual simultaneously, like going to the bank or the supermarket, dealing with money or answering the phone. They are called instrumental activities of daily living and they are assessed by the Lawton scale.

In this test, the seniors were classified into independent or dependent in the development of nine functions. They may be classified as independent, partially dependent or totally dependent for each function. The maximum score is 21 points⁽¹¹⁾.

Concerning the CDT, it is a test that assesses the visuocognitive ability or constructional praxis through the capacity of drawing or building from a certain stimulus (in our case, a verbal command)⁽¹²⁾. When the disease has already set in, the individual shows a certain difficulty in recovering complex functions, which has been detected in the majority of seniors in this study, who achieved low scores.

As for the VFT, there is also evidence about the influence played by the senior's education level⁽¹³⁾, although the data collected by the present study revealed imprecise responses to either confirm or refute such statement. The older adults showed contrasting responses and it was only possible to observe that the cognitive impairment was more related to time after the installation of AD rather than to the individual's level of education.

Regarding the characteristics of the caregivers participating in this study, as in many others, there is a predominance of women as care providers⁽¹⁴⁻¹⁵⁾. Brazil is not the only country where women are the ones who look after impaired seniors: all studies mentioned and data collected indicate that, except

for very specific cultural reasons, women are traditionally the caregivers⁽¹⁴⁻¹⁵⁾.

The fact that caregivers are mostly women at an advanced age configures another problem, since they are seniors looking after other seniors. This also restricts the quality of the care offered to the person suffering from dementia, because the caregivers often need special care as well, as regards physical efforts, hygiene, and transferring, which are part of the common limitations brought about by the ageing process⁽¹⁵⁾.

The process of being a caregiver also influences the family structure because, according to Andrade and Martins, family represents the central unit for health care and plays an important role in the care of older people⁽¹⁶⁾. Such structure is determined by a dynamics which, generally, comprises four factors: relationship, gender, physical closeness and affectional closeness⁽¹⁷⁾.

As most of the times the caregiver is the sole responsible for the care, it is also expected that they give up their jobs to dedicate themselves exclusively to the senior, needing financial support or other sources of income for their expenses and the senior's^(15,18).

All of these prevailing singularities among caregivers might also limit the care strategy of the person with dementia and, mainly, hinder the cognitive stimulation activities that are most commonly performed at home. Thus, it is the nurse's duty to reorganize the family structure⁽¹⁹⁾ and encourage the participation of all members in the care process in order not to overburden a single family member. Every family should be requested to attend workshops and to take part in the care offered to the senior at home so they can share the tasks among themselves.

In most cases, the caregivers regarded the meeting as a moment of opportunity to report feelings of sadness, lack of patience and abandonment by the other family members. Mood alterations, behavior, disorientation and irritability are very common traits among older people with dementia and, therefore, interfere in the caregivers' attitudes and experiences, making them more susceptible to events of depression and anxiety. The emotional overburden to which the caregiver is exposed might interfere in the quality of the care offered to the senior, acting as a factor that increases the number of hospitalizations and institutionalizations among the seniors, and the rate of mortality amongst caregivers⁽²⁰⁻²¹⁾.

Thus, the caregiver must find support in the health professional. Nurses must offer support, information and orientation to provide a better quality of care to the senior and for the caregivers' self-care. They are the professional therapists who, by contacting the patients, have the opportunity to provide tools like access to the service, embracement, support and

orientation, developing light care technologies by establishing bonds and humanizing care.

Study limitations

As a limitation to the present study, it is important to mention the fact that it has been a case study, since it was conducted in a limited space and with a small number of participants. Hence, the results obtained may not be taken into consideration for the total older population with dementia and their caregivers and they are not appropriate for generalizations about the benefits of home-based cognitive stimulation carried out by caregivers.

Future research is necessary on the subject of continuous cognitive stimulation in all environments experienced by older adults. Based on the experience acquired through the usage of material developed in order to qualify caregivers to conduct the home-based cognitive stimulation, it is recommendable to develop orientation guidelines and to provide training for those who are responsible for looking after seniors with dementia, so the active participation of caregivers and other family members in the senior's care is encouraged.

CONCLUSIONS

According to the results of the present study, both seniors and caregivers benefitted from the strategy implementation, since it has contributed to the caregivers' comprehension towards the relevance of the continuity of the activities commenced during the therapeutic workshops.

By introducing new practices in the care of older people with dementia, in integration with the concepts in Mehry's health technology and in the humanistic nursing theory, a nursing action which values the human being was created. The technology focusing on the continuous care of older people with dementia, having the caregiver as the connection, assumes an innovative path that generates a humanizing attitude, besides valuing the development of a new model of care, which will guide caregivers' actions.

The findings of this study can contribute to empower, inform and train these caregivers for home care and, thus, enlarge the area of relationships between professional and user, and among users, conducive to the practice of nursing care technology.

It is important to highlight that such strategy might be considered a light technology of nursing care for older people with dementia, one which needs further studies and continuous implementation among this population.

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