

Eficácia de treinamento de estratégias comunicativas a cuidadores de pacientes com demência*****

Communicative strategies training effectiveness to caregivers of patients with dementia

Francelise Pivetta Roque*

Karin Zazo Ortiz**

Mariana da Silva Câmara Araújo***

Paulo Henrique Ferreira Bertolucci****

*Fonoaudióloga. Mestre em Ciências pela Universidade Federal de São Paulo. Professora Assistente da Faculdade de Fonoaudiologia da Universidade Estadual de Ciências da Saúde de Alagoas. Endereço para correspondência: Rua Dr. José Correia Filho, 282 - Apto. 805 - Maceió - AL - CEP 57036-130. (franceliseroque@yahoo.com.br).

**Fonoaudióloga. Pós Doutorado em Neurociência pela Universidade Federal de São Paulo. Professora Adjunto da Disciplina de Distúrbios da Comunicação Humana do Departamento de Fonoaudiologia da Universidade Federal de São Paulo - Escola Paulista de Medicina.

***Fonoaudióloga. Especialista em Fonoaudiologia Hospitalar pela Faculdade Maurício de Nassau - Recife (PE). Fonoaudióloga Clínica.

****Médico Neurologista. Pós Doutorado em Neurologia pela University of London - Inglaterra. Professor Adjunto da Disciplina de Neurologia do Departamento de Neurologia e Neurocirurgia da Unifesp - EPM.

*****Trabalho realizado na Universidade Federal de São Paulo.

Abstract

Background: the communication decline in Alzheimer's disease (AD) may have a significant impact on the quality of life of demented elderly and their caregivers. This can be subsided by the use of communicative strategies. **Aim:** to evaluate the effectiveness of a communication strategies training program for caregivers of patients with moderate AD. **Method:** this study identified the use and effectiveness of communication strategies used by caregivers, prior to and after training. This was done through the analyses of a questionnaire and the videotaped interactions between caregivers and patients. The program was used with seven caregivers. **Results:** after the program the following was observed: significant statistical increase in the use of the proposed strategies, according to the reports made by the caregivers and to the observations made by the examiners; absence of statistical difference in the effectiveness of these strategies, also according to the reports made by the caregivers and to the observations made by the examiners; absence of changes in the correlation between use and effectiveness, and report of other changes related to communication. **Conclusion:** the training program was effective in changing the communicative behavior of caregivers.

Key Words: Dementia; Caregivers; Aged; Communication Disorders.

Resumo

Tema: os déficits de comunicação na doença de Alzheimer (DA) interferem na qualidade de vida do demenciado e do cuidador, mas podem ser amenizados por estratégias comunicativas. **Objetivo:** verificar a eficácia de um programa de orientação sobre estratégias comunicativas a cuidadores de idosos com DA moderada. **Método:** verificaram-se o uso e a eficácia de estratégias comunicativas, antes e depois de treinamento em grupo destas, mediante análise de questionários e interações filmadas entre cuidadores e demenciados. O programa foi aplicado a sete cuidadoras. **Resultados:** depois do programa, verificaram-se: aumento estatisticamente significante na frequência de uso das estratégias, segundo relato das cuidadoras e observação de examinadoras; ausência de diferenças estatisticamente significantes na eficácia destas estratégias, segundo relato das cuidadoras e observação de examinadoras; ausência de mudanças na correlação entre uso e eficácia, e relato de outras mudanças relacionadas à comunicação. **Conclusão:** houve eficácia do programa, uma vez que se verificaram mudanças no comportamento comunicativo dos cuidadores.

Palavras-Chave: Demência; Cuidadores; Idoso; Transtornos da Comunicação.

Artigo Original de Pesquisa

Artigo Submetido a Avaliação por Pares

Conflito de Interesse: não

Recebido em 12.03.2008.

Revisado em 29.06.2008; 31.10.2008;

24.12.2008; 27.03.2009; 3.04.2009;

17.04.2009.

Aceito para Publicação em 17.04.2009.

Referenciar este material como:



Roque FP, Ortiz KZ, Araújo MSC, Bertolucci PHF. Communicative strategies training effectiveness to caregivers of patients with dementia (original title: Eficácia de treinamento de estratégias comunicativas a cuidadores de pacientes com demência). Pró-Fono Revista de Atualização Científica. 2009 jul-set;21(3):225-30.

Introduction

Although fundamental in human relations on daily activities 1, communication is only noticed when some disorder affects it, such as Alzheimer's disease (AD) 2, the most common cause of dementia 3 both by deficits in language since the early stages of the disease 4, and by other cognitive alterations related to communication.

The growing dependence of the patient with dementia of a caregiver makes communication essential to express desires and needs - which are now served by third parts 5. Difficulties in expressing and understanding speech often result in relationship conflicts, social isolation, depression, stress and increased risk of institutionalization 6-7.

Given the high prevalence of AD in developing countries 8, the search for resources that ease this disease includes comprehensive and low cost initiatives and guidance programs for the caregivers.

Although previous studies show improvement in communication with interlocutors in aphasics after training 9-11, it is important to better know its results, particularly in the case of dementia, because of the nonexistence of conclusive studies on its effectiveness.

Thus, this study aimed to verify the effectiveness of a training program to facilitate communication strategies of caregivers of elderly patients with moderate AD.

Method

The present study (number 1098/04) was approved by the Research Ethics Committee of the Federal University of São Paulo (Universidade Federal de São Paulo). All participants signed a Term of Free and Informed Consent consenting to implementation and dissemination of this study, according to Resolution 196/96 (BRASIL. Resolution MS / CNS / CNEP Number 196/96 of October 10, 1996).

This is an analytical study of a series of cases assisted by university departments and by private practices. The study was conducted in two northeastern Brazilian capitals from November 2004 to April 2006.

It included the main caregivers of seniors with moderate AD, who were in use of glutamate receptor antagonists or acetylcholinesterase drugs inhibitors for at least three months. The diagnoses were made by geriatrician or neurologist, according to the DSM-IV criteria 12 NINCDSADRDA 13 and CDR 14. Caregivers with visual and/or hearing

disorders that prejudiced the communication between patient and caregiver were excluded. The communicative facilitative strategies used by caregivers before and after an orientation program - which aimed the training of these strategies - were investigated.

For such, a questionnaire (use and effectiveness of those strategies mentioned by caregivers) and a film recording of an interactive situation between caregiver and patient were used. The caregiver training was conducted by a Speech-Language Pathologist, and the application of the questionnaire and the analysis of films by Speech-Language Pathology students after a training (training of volunteers consisted of interview and analysis of filmed interactions not used in this study - the students were deemed suitable when records of their responses on the questionnaires of three volunteers were identical as well as the analysis of the film in ten consecutive communicative shifts).

The questionnaire was formulated based on previous study 15 and on other relevant strategies cited in the literature. Filming was conducted on at most 15 days after questionnaire application, at the home of the patients, during lunch or dinner - situation in which there was more communication between caregivers and patient according to report. Camera and tripod were positioned to enable the viewing of the communicative pair - patient caregiver - and absence of the researcher during the registration of the situation. For the speech-language orientation program, caregivers (grouped in a maximum of five, as they were included in the study) participated in four sessions with an average of an hour and a half each, considering the lowest number possible of sessions to train all strategies.

The training included a brief discussion on communication and its commitment on dementia, with audiovisual resources, writing support and dramatization.

After 7 to 21 days after the program, the investigation procedures were repeated, also questioning about other possible benefits perceived by caregivers.

The recordings were separately transcribed and analyzed by two evaluators, who did not know whether the shooting was conducted before or after intervention.

Regarding the observed use, the strategies were divided into two groups, according to the analysis possibility: Group 1, in which each strategy was considered as present or absent during filming and Group 2, in which the relative frequency of strategy presence was analyzed, represented by the ratio

between the number of communication turns in which it was used and the total turns between caregiver and patient 3.

The use of each communicative intention efficacy was overall described, without discrimination by strategy. Each communication turn of the caregiver was judged according to its effectiveness, observing the patient response. All communicative turns identified as "communication breakdowns" were identified on each recording. A ratio between the number of turns "flawed" and the total turns of the targeted caregivers was calculated, obtaining, thus an index of inefficiency rather than of efficiency. This option aimed not to overestimate the effectiveness - because of the presence of situations of uncertainty in this judgment - without being possible to conclude the communicative success or failure reported by methodological limitations. Were considered "communication breakdowns" when the response of the patient was inappropriate; and / or when other signs that the patient had not understood the message of the caregiver were verified; and / or that the expression of the patient had not been facilitated by the strategy employed, and interpreting for such conclusion, the behavior and / or facial expression of the patient.

Using the Kolmogorov-Smirnov statistical test of adherence, we observed that the non-normality

of the data. The Wilcoxon test (paired samples) was used to compare frequency and effectiveness of strategies used by caregivers, before and after intervention. The Spearman correlation was used to verify the correlation between use and effectiveness of these strategies by caregivers. Differences were considered significant when $p < 0.05$ bilateral (statistical program SPSS 13.0 for Windows).

Results

From the records, 34 patients whose caregivers could be included on the study were identified. Of these, 15 reported unavailability and / or indifference to participate, one was excluded for patient hearing difficulty, and one interrupted his participation for personal reasons. Three seniors were not using dementia medication, and the two were using it for less than three months. Two elderly people had passed away and three could not be contacted.

Thus, seven caregivers and the seven elderly people with AD taken care by them participated in this research. All caregivers were women, six daughters and a granddaughter of a dementia patient, with a mean age of 48:0 years \pm 10:0 and with mean education of 12:7 years \pm 2.9. Amongst the patients, five were women and two men, with mean age of 74:7 years \pm 8.1, and mean education of 4.3 years \pm 5:7.

TABLE 1. Medians of frequency use of communicative facilitative strategies, according to caregivers report prior and post Speech-Language Pathology orientation program.

Strategies:	Frequency of use	
	Prior	Post
1. Use of short and simple sentences	4	3
2. Slow speech	3	4
3. Ask one question or give one order at a time	2	4
4. Slow and frontal approach, or use of touch to ask for attention	3	4
5. Speak in front of with eye contact always as possible	3	4
6. Take away noises that can distract	3	4
7. Avoid to interrupt their speech	3	4
8. Ask closed questions	3	2
9. Ask open questions	1	3
10. Repeat with the same words what was not understood	2	2
11. Repeat with other words what was not understood	2	2
12. Help to remind a word, asking them to talk about what they are trying to remember	1	3
13. Use gestures and facial expression related to what is being said	3	4
14. Use speech intonation related to what is being said	1	3
15. If you are having difficulties in understanding what is being said, repeat what you think that is being said, asking whether that is what they were trying to say	2	3
16. Try to understand what they want by interpreting their behavior	3	4
17. Leave the room with clear light while speaking to them	2	4
18. Use daily situations associated to hour/time (instead of saying: "we leave in the morning" say "we leave after breakfast")	2	4
19. Use objects, pictures and writing to help comprehension	3	3
20. Other strategies	0	0

P<0.001 (Bilateral Wilcoxon Test). Legend: Frequency of use: 0 never; 1 few times; 2 approximately half of the times; 3 several times; 4 every time

Before training, five caregivers received prior information on communication in dementia, by reading specific materials and / or by orientation of health professionals and / or mass media. They mentioned that during the training, they still continue obtaining information on the subject by other means. There was a statistically significant increase in the use of strategies reported and observed, as shown in Tables 1, 2 and 3.

Regarding efficacy, there was no statistically significant difference after the program, nor regarding the effectiveness mentioned ($p=0.276$) or observed ($p=0.310$).

Positive Spearman correlation was observed between the use and effectiveness of these strategies by caregivers, before the program ($r=0,413$, $p<0001$), and after it ($r=0,351$, $p<0001$). All caregivers reported positive impact of training on the communication manner, on their relations with the elderly, and on the performance of daily activities. They affirmed to be more "calm" and have more "patience" (SIC) to deal with their relatives, mentioning a reduction in episodes of physical aggression practiced by their mother.

Discussion

Studies with identical methods were not found, limiting the comparison to the literature. Orientation programs for dementia caregivers focused on cognitive and behavioral skills besides communication and / or used other measures other than the verification of use and effectiveness of the trained strategies, as in the present study 16-21.

It is important to observe the denial for participation in this study of much of the initial sample (44.11%). This was an intervention which benefits could be immediately applied to daily life, and maintained without financial burden, or submission to invasive procedures. One hypothesis is the lack of awareness of the communication problems on the part of caregivers, who denied, on the phone, the communication difficulties of dementia - which differs from other studies in which the communication was considered the main problem²² with negative interference in daily activities. Another hypothesis is that they attach little importance to communication in comparison to other limitations, as previously observed⁷. One can still consider that, for these caregivers, the program would be one more task to be performed, with supporting statistics that 80% of these caregivers have stress^{23,24}.

TABLE 2. Proportion of caregivers who utilized the communication strategies from Group 1, according to analyzes of recordings, prior and post the program of Speech-Language Pathology orientation.

	Proportions of use (%)	
	Prior	Post
2. Slow speech	85.7	100.0
5. Speak in front of with eye contact always as possible	71.4	85.7
6. Take away noises that can distract	42.8	71.4
7. Avoid to interrupt their speech	85.7	100.0
13. Use gestures and facial expression related to what is being said	28.6	57.1
14. Use speech intonation related to what is being said	71.4	71.4
17. Leave the room with clear light while speaking to them	85.7	100.0

$p=0.026$ (Bilateral Wilcoxon Test)

TABLE 3. Proportion of caregivers who utilized the communication strategies from Group 2, according to analyzes of recordings, prior and post the program of Speech-Language Pathology orientation.

Strategies	Proportions of use (%)	
	Prior	Post
1. Use of short and simple sentences	54.5	64.1
3. Ask one question or give one order at a time	23.0	24.9
4. Slow and frontal approach, or use of touch to ask for attention	6.3	7.3
8. Ask closed questions	29.9	32.1
9. Ask open questions	8.1	8.0
10. Repeat with the same words what was not understood	2.0	2.6
11. Repeat with other words what was not understood	0.0	0.4
12. Help to remind a word, asking them to talk about what they are trying to remember	0.0	0.0
15. If you are having difficulties in understanding what is being said, repeat what you think that is being said, asking whether that is what they were trying to say	0.4	0.0
16. Try to understand what they want by interpreting their behavior	1.1	1.7
18. Use daily situations associated to hour/time (instead of saying: "we leave in the morning" say "we leave after breakfast")	0.1	0.0
19. Use objects, pictures and writing to help comprehension	0.0	0.0
20. Other strategies	0.0	1.1

$p=0.018$ (Bilateral Wilcoxon Test)

Despite the small size of this sample, this corresponded to all subjects that could be included in the period and at the location of the study.

As shown in the results, all the caregivers in this study were women, daughters and granddaughters of those cared by them, coinciding with the literature, in which caregivers are often daughters or wives²⁵.

Age and education of the elderly with AD in this study varied substantially: factors affecting cognitive status and, consequently, communication. Most of the participants with dementia were women, coinciding with populational studies²⁶. The increase in the use of such strategies (Table 1) indicated that although the caregivers use several strategies, they began to use them more often, increasing the opportunities to facilitate communication. This increase was also observed in the analysis of interactions (Tables 2 and 3), confirming data from questionnaires. As conversation results from collaborative interactions of participants - $p = 0018$ (bilateral Wilcoxon test) - 5 they have an inherent potential as active co-contributors to use strategies to achieve participation²⁷. Despite the intuitive use of such strategies^{15, 28}, ongoing training and reflection actions were more effective when compared to the provision of guidance by flyers²⁰, demonstrating the benefits of educational actions. Studies on training of aphasic communication partner also identified changes in the communicative behavior of those and positive effects on the response after the implementation of guidelines, although the different methodology applied⁹⁻¹¹.

Regarding the absence of differences on use efficacy referred and observed, on the one hand we can infer that the increase in the frequency of strategies did not result in improvement on communication effectiveness. On the other hand, these results may be a consequence of the non-representativeness of the population from this sample as well as methodological limitations of the study: on the referred effectiveness, it was questioned about the attributed effectiveness of each strategy, irrespective of its use; for the fact of these being caregivers probably more educated and aware of communication, even if they did not have

awareness about the effectiveness of a particular strategy, just the act of questioning could lead them to reflect about it, resulting on the high scores of efficiency mentioned, even before the intervention. In relation to the efficacy observed by examiners, there are three hypothesis: as filming was conducted in a short period after the training, the caregivers may not have had time to verify which strategies were actually more effective, increasing the use without a differentiation on effectiveness. The second hypothesis is the need to film more interactive situations, increasing the likelihood of communicative contexts and use of other strategies not used by lack of opportunity, such as the use of everyday situations to refer to time. The third hypothesis is that the method used to determine the effectiveness may not be sufficient to analyze the quality of communication.

The correlation between the use and effectiveness referred shows that caregivers in this sample appear to use more strategies that they identify being more effective, coinciding with previous studies²⁸. The non-increase of this correlation after the training period may be due to the good performance of this sample before the program, indicating the need for more elaborate training methods, such as monitoring the implementation of these techniques in loco¹⁷.

Considering that one way to define the effectiveness of communication management is to measure the frustration of communication experience between caregiver and patient and the alteration on burden²⁹, the caregiver reports about changes in other aspects also indicate the effectiveness of the program. The decrease on behavioral disorders after educational programs is described in the literature, evidencing that communication is critical to maintain family relationship, although it is not its alteration that causes the stress, but the decurrent behavioral problems^{7,18}.

Conclusion

For this sample, the program was effective in promoting changes on the communicative behavior of caregivers, with an increase in the use of strategies.

References

1. Richter JM, Roberto KA, Bottenberg DJ. Communicating with persons with Alzheimer's disease: Experiences of family and formal caregivers. *Arch Psychiatr Nurs.* 1995;9(5):279-85.
2. American Speech-Language Hearing Association. *The Roles of Speech-Language Pathologists working with individuals with dementia-based communication disorders: position statement.* Rockville, MD: Author; 2005. Available from <http://www.asha.org/members/deskref-journal/deskref/default>.
3. Herrera E, Caramelli P; Silveira AS, Nitrini R. Epidemiologic survey of dementia in a community-dwelling Brazilian population. *Alzheimer Dis Assoc Disord.* 2002;(2):103-8.
4. Ortiz KZ, Bertolucci PHF. Alterações da linguagem nas fases iniciais da doença de Alzheimer. *Arq Neuropsiquiatr.* 2005;63:311-7.
5. Small JA, Geldart K, Gutman G. Communication between individuals with Alzheimer's disease and their caregivers during activities of daily living. *Am J Alzh Dis. Other Demen.* 2000;15:291-302.
6. Steeman E, Abraham IL, Godderis J. Risk profiles for institutionalization in a cohort of elderly people with dementia or depression. *Arch Psychiatr Nurs.* 1997;11:295-303.
7. Savundranayagam MY, Hummert ML, Montgomery RJV. Investigating the effects of communication problems on caregiver burden. *J Gerontol B Psychol Sci Soc Sci.* 2005;60B(1):S48-S55.
8. Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, et al. Global Prevalence of dementia: a elphi consensus study. *Lancet.* 2005;366:2112-7.
9. Kagan A, Black SE, Duchan JF, Simmons-Mackie N, Square P. Training Volunteers as Conversation Partners Using "Supported Conversation for Adults With Aphasia"(SCA): A Controlled Trial. *J Speech Lang Hear Res.* 2001;44:624-38.
10. Rayner H., Marshall J. Training volunteers as conversation partners for people with aphasia. *Int J Lang Commun Disord.* 2003;2:149-64.
11. Machado TH. Eficácia de um programa de orientação para cuidadores de afásicos em população brasileira [dissertação]. São Paulo: Universidade de São Paulo; 2004.
12. Manual diagnóstico e estatístico de transtornos mentais: DSM-IV. 4ª ed - texto revisado[DSM-IV-R]. Traduzido por Batista D. Porto Alegre: Artmed; 2002.
13. McKhann G, Drachman D, Folstein M, et al. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA work group under the auspices of department of health and human services task force on Alzheimer's disease. *Neurology.* 1984;34:939-44.
14. Berg L. Clinical dementia rating. *Psychopharmacol Bull.* 1988;24:637-9.
15. Small JA, Gutman G. Recommended and reported use of communication strategies in Alzheimer caregiving. *Alzheimer Dis Assoc Disord.* 2002;16(4):270-8.
16. Ripich DN, Wykle M, Niles S. Alzheimer's disease caregivers: the FOCUSED program. *Geriatr Nurs.* 1995;16:15-9.
17. Ripich DN, Kercher K, Wykle M, Sloan DM, Ziol E. Effects of communication training on African-American and white caregivers of persons with Alzheimer's disease. *J Aging Ethnicity.* 1998;1:163-78.
18. McCallion P, Toseland RW, Lacey D, Banks S. Educating nursing assistants to communicate more effectively with nursing home residents with dementia. *Gerontologist.* 1999;39:546-58.
19. Burgio LD, Allen BR, Roth DL, Bourgeois MS, Dijkstra K, Gerstle J, et al. Come talk with me: improving communication between nursing assistants and nursing home residents during care routines. *Gerontologist.* 2001;41:449-60.
20. Done DJ; Thomas JA. Training in communication skills for informal carers of people suffering from dementia: a cluster randomized clinical trial comparing a therapist led workshop and a booklet. *Int J Geriatr Psychiatry.* 2001;16(8):816-21.
21. Bottino CMC; Carvalho IAM; Alvarez AMMA; Ávila R; Zuzauskas PR; Bustamante SEZ, et al. Reabilitação cognitiva em pacientes com doença de Alzheimer - Relato de trabalho em equipe multidisciplinar. *Arq Neuropsiquiatr.* 2002;60(1):70-9.
22. Rundqvist EM. Caring relationships with patients suffering from dementia: An interview study. *J Adv Nurs.* 1999;29(4):800-7.
23. Zarit SH, Gaugler JE, Jarrott Se. Useful services for families: research, findings and directions. *Int J Geriatr Psychiatry.* 1999;14:165-81.
24. Alzheimer's Association and National Alliance for Caregiving. *Who cares? Families caring for persons with Alzheimer's disease.* Bethesda: National Alliance for Caregiving; 2000.
25. Grunfeld E, Glossop R, McDowell I, Danbrook C. Caring for elderly people at home: the consequences to caregivers. *Can Med Assoc J.* 1997;157:1101-5.
26. Corrêa ACO. A doença de Alzheimer. In: _____. *Envelhecimento, depressão e doença de Alzheimer.* Belo Horizonte: Health; 1996. p.135-89.
27. Oelschlaeger ML, Damico JS. Partnership in conversation: a study of word search strategies. *J Commun Disord.* 2000;33(3):205-23,223-5.
28. Small JA, Gutman G, Hilhouse SMB. Effectiveness of communication strategies used by caregivers of persons with Alzheimer's disease during activities of daily living. *J Speech Hear Res.* 2003;46:353-67.
29. Clark LW, Witte K. Nature and efficacy of communication management in Alzheimer's disease. In: Ripich D, editor. *Dementia and communication.* Philadelphia: B.C. Decker; 1995. p.238-55.