Therapeutic Patient Education in Alzheimer's Disease: Addressing the Challenges of the Dyad

HÉLÈNE VILLARS[1,2], PHILIPPE GIRARD[1]

Care Weekly 2018;2:9-13

http://dx.doi.org/10.14283/cw.2018.7

1. Toulouse University Hospital, Department of Geriatric Medicine, F-31059, Toulouse France
2. Inserm 1027, University of Toulouse III, F-31073, Toulouse France

Corresponding to: Dr Hélène Villars, Toulouse University Hospital, Department of Geriatric Medicine, Pavillon Albarède Place Baylac 31300 Toulouse, Fax: 00.33.5.61.77.64.86 Phone: 00.33.5.61.77.64 55
E-mail: villars.h@chu-toulouse.fr

Abstract

Psychoeducational approaches such as Therapeutic patient education (TPE) have increased substantially in the field of Alzheimer's disease. There is evidence to think they can be useful for both patients and caregivers. Such approaches, addressing the patient and the caregiver's needs, have to be designed in keeping the challenges of the dyad (patient/caregiver) in mind. This article summarize the most important results in the literature, as regards the impact of psychoeducational interventions as TPE on caregivers 'outcomes (stress, well-being, health in general) but also patient's outcomes (quality of life, behaviour). Person-centered and tailored informations delivered to caregivers by specifically trained professionals using pedagogic methods and innovative tools, could improve the quality of care delivered to AD patients. TPE seems to have a place in an integrated care type of approach for AD patient's and caregivers.

Key words: **Therapeutic education, Alzheimer's disease, caregiving, non-pharmacological interventions, person-centered approach, quality of life.**

Introduction

Psychoeducational interventions for caregivers of patients affected with Alzheimer's disease (AD) have increased substantially for almost two decades (1-12). During this time, educational programs and behavioral interventions targeting the cognitively impaired subjects themselves have also flourished (13-16). Currently, some authors consider that the dyad (patient/caregiver) is the 'real beneficiary' of these approaches (17, 18). During the course of AD each dyad experiences changes and, unfortunately a decline in the quality of interpersonal relationships in most instances. Therefore, each dyad can be considered as having its own challenges. In our opinion, there is a need to design and evaluate intervention programs with the challenges of the dyad in mind.

Place of Therapeutic Patient and Caregiver Education in Alzheimer's Disease

In this field, therapeutic patient education (TPE) can bring part of a solution by considering the dyad as the real "patient" -as a concept- and targeting their unique needs. Therapeutic patient education (TPE) is a basic, lasting component of patient management, according to the World Health Organisation definition (WHO) (19). It was developed in the field of diabetes management in the early 1980s, and has shown its efficiency in many chronic diseases. TPE covers organized activities designed to make patients and their relatives fully aware about their disease. TPE helps patients and their relatives acquire or maintain the skills they need to manage their life with a chronic disease. It focuses on empowering the subject and his or her family to find the resources, to cope with the consequences of the disease in their life. The content is individually tailored, based on pedagogic methods and tools, performed by a multidisciplinary team of health professionals, specifically trained. Tools are represented by, for example, storytelling, drawings, videos, quizzes etc… that allow the professionals to explore the subject's representations and worries (19-21). It has been demonstrated that this non-pharmacological approach can lead to changes in patient's lifestyle and behaviors in many chronic diseases. Indeed, the WHO has listed almost 60 chronic conditions in which such an approach can be proposed. In those conditions, studies have shown a positive impact on patients' self-management behavior, notably on adherence to medication regimen (22) and health behaviors in general (23-25). The efficacy of TPE has been proven to modify behaviors and promote changes in life, for example in diabetes and asthma (26, 27).

Due to the specific characteristics of AD: cognitive impairment, especially memory loss, and anosognosia it has been difficult to implement such programs in the field of AD, initially. The patient's skills to acquire abilities to modify his/her behaviour were unfortunately supposed to be so far impaired that it constituted a barrier to implementation. For this reason, the caregiver was initially considered as the only beneficiary of TPE programs. In the literature, positive studies with outcomes on caregiver's physical and mental health started to appear almost 20 years ago. It has been shown that the caregiver's burden decreases after a psychoeducational intervention and that his or her knowledge, feeling of competence, well-being and quality of life is improved (2). Several studies have demonstrated that such educational programs can improve the caregiver's quality of life or decrease his/her feeling of depression and burden (4, 8-11).

At the present time some authors consider that the patient, too often excluded from any educative relationship with the physician, also has to be included in this approach. Indeed the diagnosis is increasingly made at an early stage of the disease that allows him/her to be engaged in this type of partnership. Furthermore, from an ethical point of view, there is a need to deliver information and to propose support to the patient him or herself. Only few studies have evaluated the effectiveness of multidimensional psychoeducation interventions on the AD patient him/herself (2, 3, 15, 16) because of the barrier we underlined earlier. The most effective interventions are the multi-dimensional ones, including a formalized psychoeducational program for caregivers associated, as appropriate, to respite, psychological support and / or pharmacological treatment addressed to the patient (17, 18). There is evidence demonstrating that these interventions can reduce patient's behavioral and psychological symptoms of dementia (BPSD) (17, 18). When therapeutic education is combined with respite care or psychological support, the patient's quality of life is increased (17). Unfortunately, there are also negative studies. A randomized controlled trial, DAISY, conducted in Denmark, demonstrated that a psychosocial counselling and support program for outpatients with mild Alzheimer's disease and their primary caregivers induced a small and non-significant improvement of the patient's depression (13). Cognitive functions and autonomy are unfortunately difficult to improve, as an outcome, in such studies results (13, 14).

Even if there is a current need to involve patients, caregivers are still at the heart of this approach the pivot de la demarche. It is well known for example that TPE programs can modify caregiver's or relatives' attitudes. This is not only true in geriatric care but also in pediatric care (28) and psychiatric care (29-31). Indeed by transmitting knowledge, expertise and skills to the relative or to the caregiver, he/she is able to modify his/her behavior with the patient.

Thus, there are reasons to think that the dyad is the beneficiary of psychoeducational approaches. One the one hand, interventions that jointly engage community dwelling people with AD and their caregivers in education and training are the most successful (17). On the other hand, it is known that family caregivers of demented patients benefit from a psychoeducational program more than a "direct" information transfer through the extensive offer of self-help literature (3) in the way they communicate, in their emotional attitude towards the patient and their perceived burden and symptoms of depression (3). TPE addressed to both caregivers and patients seems to be of benefit for each member of the dyad (patient/caregiver). As a matter of fact, this approach has become, recently, one of the components of the care of Alzheimer's disease (AD) affected patients and their caregivers, in international guidelines (32-34). In France, for example, it is one of the key components of the French national public Health plan 2014 2019 (34).

Even if it is recommended in routine care, there is still a need of additional evidence to strengthen the rationale to implement it more widely. When designing a trial to evaluate the impact of a TPE program on each member of the dyad, some aspects are to be considered carefully.

Concerning the intervention in itself, there are compulsory elements. In existing trials, the content always includes problem-solving techniques and coping strategies, counselling on management of patient's behaviours and crisis management dealing with role change and obtaining support. A TPE intervention is as much as possible tailored to the individual's personality, beliefs, needs and requests. The person is led to formulate a project by identifying skills to acquire or to strengthen and by defining realistic goals to reach during the program and afterwards in her/his life with the patient. Indeed tools and methods are defined and validated in TPE (19-21).

The "format" is often standardized in the form of "structured sessions" (for example2h once a week for X number of weeks addressed to caregivers) in small groups of 6 persons but the frequency and the duration is very varied. A few interventions are based on lectures that are less interactive than educational group sessions. Internet-based interventions are a novel format of education and counselling, but also support (4, 35, 36). Some programs are web-based courses, e-learning program or MOOCS. Information and communication technologies (ICT) are nowadays one of the major components of pedagogic activities (36) (computer-based activities and brainstorming, MOOC, chats etc…) now commonly used in health education that are promising in the field of patient education (36). The way information and knowledge is delivered is, in our opinion, an important aspect of the potential effect of this type of intervention. There is evidence leading to think that web-based interventions can be of great value. A recent randomised controlled trial has shown that a web-based learning course increases empathy and understanding of dementia caregivers (35).

The potential limitations are known (accessibility, usability, acceptability), but ICT are now an indispensable tool to be used in TPE, in a shared information and shared decision, integrated care approach.

Concerning the judgement criteria, there is a need to find the most relevant judgement criteria of the impact of TPE on the dyad. The patient's mood, BPSD, physical health or quality of life could be of great interest. As an example, quality of life is a multidimensional and relevant criterion in the management of chronic diseases, now used in the field of dementia (37). The decline in quality of life at mild stages of the disease is due to cognitive function (38) on which educational interventions have not demonstrated any positive impact (13) but later, those same interventions could have an impact. Depressive mood and polypharmacy are two factors also influencing quality of life in patients with AD (39). To estimate their quality of life, proxy reports are sometimes used introducing bias as the caregiver's representations might influence the assessment (40-44). It is important to assess both self and caregiver ratings when assessing patients QOL (44). This is true for every judgment criteria heteroevaluated by the caregiver. Caregiver's stress, mood or feeling of burden are currently the main chosen outcomes (6, 11, 12). The caregiver's mental load or quality of life have also been studied (10). Finally, dementia's health related costs are studied. Reducing caregiver's depression with educational tools for example reduces health costs (45).

Concerning the actual and future place of TPE in dementia care, nowadays, pharmacological treatments, antidementia or antipsychotic drugs are not sufficiently efficient or associated with adverse effects (46, 47). Non-pharmacological therapeutics are thus at the forefront (33, 48, 49). Among them, psychoeducational approaches could become key. Indeed, they are recommended by international guidelines as first line care (32, 33, 48, 49). TPE addressed to the dyad is recommended in the French National plan (34) but we need to consider their generalization at the moment of design in order to make them reproducible, evaluable and cost-effective. Delivering expertise, knowledge, skills and support to caregivers, through psychoeducational approaches is a long and expensive process for which health professionals need to be trained. Nevertheless, from our point of view, this approach needs to be continued because it could lead to better physical and mental health in caregivers, especially for our eldest patients. In many EU countries family members have shouldered the caregiving responsibilities, which can lead to inequalities, for example by taking a member of the family out of the workforce and, lessen his/her economic situation (50). This could also lead to less inequality, as women are often the main caregivers.

Conclusion

In our aging societies, considering the lack of pharmacological treatment in the field of AD and the burden shouldered by caregivers, it can be envisaged that psychoeducational approaches addressed to both patients and caregivers be part of the care plan in AD and even at the heart of an integrated care type of approach. When designing TPE programs we need to keep the challenges of the dyad (patient/caregiver) in mind, that is to say, creating them tailored and person-centered, in an acceptable but also innovative format (ICT), in choosing the way we evaluate their efficiency for each member of the dyad. TPE of the dyad needs to be designed, from the onset, to be feasible in daily care routine, generalizable and cost-effective with sustainability in mind, because of our health care organizations and reimbursement systems, which hadn't integrated, at their conception, the 21st century longevity rates (51).

Conflict of Interest

None.

References

1. Gitlin LN. Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: a randomized pilot study. The American Journal of Geriatric Psychiatry. 2008;16(3):229-239.
2. Piersol CV, Canton K, Connor SE, et al. Effectiveness of Interventions for Caregivers of People With Alzheimer's Disease and Related Major Neurocognitive Disorders: A Systematic Review. Am J Occup Ther. 2017; 71(5):1-10
3. Engel S, Reiter-Jäschke A, Hofner B. "EduKation demenz®". Psychoeducative training program for relatives of people with dementia]. Z Gerontol Geriatr. 2016; 49(3):187-195.
4. Martin-Carrasco M, Martin MF, Valero CP, et al. Effectiveness of a psychoeducational intervention program in the reduction of caregiver burden in Alzheimer's disease patients' caregivers. Int J Geriatr Psychiatry 2009; 24: 489-499.
5. Cristancho-Lacroix V, Kerhervé H, de Rotrou J, et al. Evaluating the efficacy of a web-based program (diapason) for informal caregivers of patients with Alzheimer's disease: protocol for a randomized clinical trial. JMIR Res Protoc, 2013 2 e55. doi: 10.2196/resprot.2978.
6. Signe A, Elmståhl S. Psychosocial intervention for family caregivers of people with dementia reduces caregiver's burden: development and effect after 6 and 12 months. Scand J Caring Sci 2008; 22, 98-109.
7. Gerdner LA, Buckwalter KC, Reed D. Impact of a psychoeducational intervention on caregiver response to behavioral problems Nurs Res 2002; 51: 363-374.
8. Sorensen S, Pinquart M, Duberstein P-O. How effective are interventions with caregivers?an updated meta-analysis. Gerontologist 2002; 42: 356-372.
9. Devor M, Renvall M. An educational intervention to support caregivers of elders with dementia. Am J Alzheimers Dis Other Demen 2008; 23: 233-241.
10. Kuzu N, Beser N, Zencir M, Sahiner T, et al. Effects of a comprehensive educational program on quality of life and emotional issues of dementia patient caregivers. Geriatr Nurs 2005; 26: 378-386.
11. Tompkins AS, Bell. Examination of a psychoeducational intervention and a respite grant in relieving psychosocial stressors associated with being an Alzheimer's caregiver. J Gerontol Soc Work 2009; 52: 89-104.
12. Brodaty H, Green A, Koshera A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. J Am Geriatr Soc 2003; 51: 657-664.
13. Waldorff FB, Buss DV, Eckermann A, Rasmussen ML, et al. Efficacy of psychosocial intervention in patients with mild Alzheimer's disease: the multicentre, rater blinded, randomised Danish Alzheimer Intervention Study (DAISY). BMJ 2012; 345: e4693. doi: 10.1136/bmj.e4693.
14. de Rotrou J, Cantegreil I, Faucounau V, et al. Int J Geriatr Psychiatry 2011; 26: 833-842.
15. Callahan CM, Boustani MA, Unverzagt FW, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. JAMA 2006; 295: 2148-2157.
16. Bruvik FK, Allore HG, Ranhoff AH, Engedal K. The effect of psychosocial support intervention on depression in patients with dementia and their family caregivers: an assessor-blinded randomized controlled trial. Dement Geriatr Cogn Dis Extra 2013; 386-397.
17. Smits CH, de Lange J, Dröes RM, et al. Effects of combined intervention programmes for people with dementia living at home and their caregivers: a systematic review. Int J Geriatr Psychiatry 2007; 22: 1181-1193.
18. Hinchliffe AC, Hyman IL, Blizard B, Livingston G. Behavioural complications of dementia: can they be treated? Int J Geriatr Psychiatry 1995; 10: 839-847.
19. Therapeutic patient education: continuing education programs for health care providers in the field of prevention of chronic diseases: report of a WHO Working Group / World Health Organization (1998). Regional Office for Europe. Available from http://www.euro.who.int/__data/assets/pdf_file/0007/145294/E63674.pdf
20. Bruttomesso D, Gagnayre R, Leclercq D, et al. The use of degrees of certainty to evaluate knowledge. Patient Educ Couns 2003; 51: 29-37.
21. Bodenheimer T.Disease management promises and pitfalls. N England J Med 1999; 340 : 1202-1205
22. Rueda S, Park-Wyllie LY, Bayoumi AM, et al. Patient support and education for promoting adherence to highly active antiretroviral therapy for HIV/AIDS. Cochrane Database Syst 2006 Rev 19, CD001442.
23. Moradkhani A, Kerwin L, Dudley-Brown S,Tabibian JH. Disease-specific knowledge, coping, and adherence in patients with inflammatory bowel disease. Dig Dis Sci 2011 ; 56: 2972-2977.
24. Meng K, Seekatz B, Haug G etal .Evaluation of a standardized patient education program for inpatient cardiac rehabilitation: impact on illness knowledge and self-management behaviors up to 1 year. Health educ Res 2014; 29: 235-246.
25. Li T, Wu HM, Wang F, et al. Education programmes for people with diabetic kidney disease. Cochrane Database Syst Rev 2011;15, CD007374.
26. Norris SL, Engelgau MM, Narayan KM. Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials. Diabetes Care 2001; 24: 561-587.
27. Gibson PG, Powell H, Coughlan J, et al. Self-management education and regular practitioner review for adults with asthma. Cochrane Database Syst Rev 2003; 1, CD001117.
28. Williams KW , Word C, Streck MR, Titus MO. Parental education on asthma severity in the emergency department and primary care follow-up rates. Clin 2013; 52: 612-619.
29. Pitschel-Walz G, Bäuml J, Bender W, et al. Psychoeducation and compliance in the treatment of schizophrenia: results of the Munich Psychosis Information Project Study. J Clin Psychiatry 2006; 67: 443-452.
30. Xia J , Merinder LB, Belgamwar MR. Psychoeducation for schizophrenia. Cochrane Database Syst Rev 2011; 15, CD002831.
31. Shimodera S, Furukawa TA, Mino Y, et al. Cost-effectiveness of family psychoeducation to prevent relapse in major depression: results from a randomized controlled trial. BMC Psychiatry 2012; 14: 12-40.
32. Salzman C, Jeste D, Meyer RE, et al. Elderly patients with dementia-related symptoms of severe agitation and aggression: consensus statement on treatment options, clinical trials methodology, and policy. The Journal of Clinical Psychiatry. 2008;69:889.
33. Gauthier, S. et al. Management of behavioral problems in Alzheimer's disease. International Psychogeriatrics, 2010; 22: 346–372.
34. https://www.has-sante.fr/portail/upload/docs/application/pdf/2018-05/parcours_de_soins_alzheimer.pdf
35. Hattink B, Meiland F, van der Roest H, et al Web-Based STAR E-Learning Course Increases Empathy and Understanding in Dementia Caregivers: Results from a Randomized Controlled Trial in the Netherlands and the United Kingdom.J Med Internet Res. 2015; 17: 10.
36. Kurz A, Bakker C, Böhm M, Diehl-Schmid J et al. RHAPSODY - Internet-based support for caregivers of people with young onset dementia: program design and methods of a pilot study. Int Psychogeriatr. 2016; 28(12):2091-2099.
37. Schölzel-Dorenbos CJ, Ettema TP, Bos J, et al Evaluating the outcome of interventions on quality of life in dementia: selection of the appropriate scale. Int J Geriatr Psychiatry 2007; 22, 511-519.
38. Logsdon RG, Gibbons LE, McCurry SM, Teri L. Assessing quality of life in older adults with cognitive impairment. Psychosom Med 2002; 64, 510-519.
39. Barbe C, Jolly D, Morrone I, et al. Factors associated with quality of life in patients with Alzheimer's disease. BMC Geriatr. 2018; 9: 18:159
40. Rabins PV, Black BS. Measuring quality of life in dementia: purposes, goals, challenges and progress. Int Psychogeriatr 2007; 19:401-407.
41. Gerritsen DL, Dröes RM, Ettema TP, Bet al. Quality of life in dementia, opinions among people with dementia, their professional caregivers, and in literature. Tijdschr Gerontol Geriatr 2010; 41: 241-255.
42. Sousa MF, Santos RL, Arcoverde C, et al. Quality of life in dementia: the role of non-cognitive factors in the ratings of people with dementia and family caregivers. Int Psychogeriatr 2013; 25: 1097-1105.
43. Sands LP, Ferreira P, Stewart AL, Brod M, Yaffe K. What

explains differences between dementia patients' and their caregivers' ratings of patients' quality of life? Am J Geriatr Psychiatry 2004; 12: 272-280.

44. Andrieu S, Coley N, Rolland Y, et al. Assessing Alzheimer's disease patients' quality of life: Discrepancies between patient and caregiver perspectives. Alzheimers Dement. 2016; 12:427-437.
45. Dietl M, Kornhuber J, Schöffski O, Grässel E.Cost-effectiveness model of a community-based service for dementia caregivers. Gesundheitswesen. 2010; 72:99-105.
46. Maher AR, Maglione M, Bagley S, et al. Efficacy and comparative effectiveness of atypical antipsychotic medications for off-label uses in adults: a systematic review and meta-analysis. JAMA. 2011; 306:1359-1359.
47. Langballe EM, Engdahl B, Nordeng H, Ballard C, Aarsland D, Selbæk G. Short- and Long-Term Mortality Risk Associated with the Use of Antipsychotics Among 26,940 Dementia Outpatients: A Population-Based Study. Am J Geriatr Psychiatry. 2014; 4:321-323.
48. Livingston G, Kelly L, Lewis-Holmes E, et al. A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia. Health Technology Assessment. 2014; 18:39.
49. NICE. Dementia: assessment, management and support for people living with dementia and their carers: National Institute for Health and Clinical Excellence: Social Care Institute for Excellence, editor. London: National Institute for Health and Clinical Excellence; June 2018.
50. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS (2014) Caregiver burden: a clinical review. JAMA 2014; 12: 1052-1060.
51. Baumgardt J, Radisch J, Touil E et al. Aspects of sustainability in outpatient health care for demented individuals. Psychiatr Prax. 2014; 41:424-431.