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TITLE:

Therapeutic patient education in Alzheimer's disease and related disorders: clinical experience and perspectives.

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Résumé

Therapeutic patient education (TPE) is the process by which health professionals impart information to help patients self-manage their chronic disease: it is an essential part of treatment of long-term diseases and conditions. Memory loss and other cognitive disorders are usually considered as obstacles to TPE for patients with Alzheimer's disease or related disorders (ADRD). Over 100 patients with different forms of ADRD and caregivers have benefited from TPE programs since 2011 at the University Memory Clinic of Limoges. Participants report better understanding of the disease and improved relationships. TPE may prevent anxiety and depression in patient and in caregivers, and reduce burden of caregivers. General guidelines and perspectives for TPE in ADRD are outlined.

Keywords : caregivers; Alzheimer's disease and related disorders; chronic disease; patient education; depression and anxiety

1. Introduction

Therapeutic patient education (TPE) is the process by which health professionals impart information to help patients self-manage their chronic disease. TPE is designed to train self-managing and coping skills to patients: it is an essential part of treatment of long-term diseases and conditions (1).

The ongoing French National Health Plan recommends TPE for people affected by neurodegenerative disorders. Whereas TPE programs are well defined for Parkinson's disease (2), for multiple sclerosis (3) and for Huntington's disease (4), there is yet little experience of TPE for dementia patients.

Memory loss and other cognitive disorders due to Alzheimer's disease or related disorders (ADRD) are usually considered as obstacles to TPE. Many programs address the family caregivers of people with ADRD, but not the people themselves (5). At our Clinical and Research Memory Center (CRMC), people with ADRD and their caregivers have benefited from TPE programs since 2011; this paper reports the clinical experience and suggests general guidelines for TPE in ADRD.

2. MATERIAL AND METHODS

2.1 The beginning of the project. In 2010, several people with posterior cortical atrophy (PCA) were diagnosed at the CRMC. Because PCA syndrome is a rare condition, a support group was organized for the people with PCA and their caregivers. The exchanges occurring during the support group meetings revealed that people with PCA were able to adopt coping attitudes and strategies and that sharing their experience was very positive for their self-esteem (6). This experience incited professionals to elaborate a TPE program for people with ADRD, which was authorized by the Local Health Agency and started in 2011.

2.2. Participants: The ADRD diseases targeted were "orphan diseases" such as PCA, non-fluent and logopenic forms of primary progressive aphasia (PPA), behavioral fronto-temporal lobar degeneration (FTLD) and also early onset Alzheimer's disease (EOAD). These rare disorders are more inclined to cause isolation, anxiety and misunderstanding because they are generally unknown by the general public and by primary healthcare professionals. People with these rare disorders and caregivers find it difficult to understand and to accept their disease.

People with these ADRDs were pre-selected from the CRMC outpatient file according to their diagnosis, using the criteria defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). For each person with ADRD, the main family caregiver was included in the TPE program.

People with ADRD who did not acknowledge their disease because of pronounced anosognosia or denial were not included in the program. People with ADRD who were not able to give their written consent because of their cognitive deterioration were also excluded from TPE. In these cases of non-inclusion, a family support program was offered to their caregivers. In some cases, people with ADRD and their caregivers did not wish to participate because of the distance from their home to the CRMC or because they felt constrained by the TPE program schedule.

2.3. TPE groups: Preselected people with ADRD and their family caregivers were informed about the TPE program during follow-up at the CRMC. Those interested were interviewed by one of the neuropsychologists who gave detailed information about the program and collected written consent. The neuropsychologist then established for each participant (person with ADRD and caregiver separately) an individual educational needs assessment describing the participant's objectives for TPE (figure 1).

Thus, groups of people suffering from the same ADRD (or the same syndrome), with similar degrees of cognitive deterioration, accompanied by one or two family caregivers, were formed; groups did not exceed 15 participants.

2.4. The TPE professional team: The ADRD TPE program was coordinated by a specialized neurologist of the CRMC. During a TPE session, one of the neuropsychologists of the team became the referent for the group: this professional conducted the initial and final assessments and was present at every meeting. At least two professionals of the TPE team were present at every meeting conducted by the referent neuropsychologist: the neurologist, the nurse or other psychologists of the CRMC. All the professionals of the team had been trained for TPE. Other professionals such as social workers or speech therapists were invited for special meetings when needed.

2.5. The TPE sessions: Separate sessions were designed for each ADRD: PCA, PPA, FTLD and EOAD. The sessions consisted of eight monthly meetings (Table 1) with the referent neuropsychologist and one or more other member of the TPE team. A light snack was offered at the beginning and the end of each meeting to help the participants feel welcome and relaxed.

The first meeting was always dedicated to introducing the program as well as all the professionals of the TPE team and all the participants. It was important to create group cohesion and reduce the stress by underlining common points among the participants. The next meetings were dedicated to explaining the effect of the disease on the brain, and the symptoms and changes due to the disease. As the meetings went, participants were encouraged to discuss their own difficulties and ask their questions in an open manner. Most meetings were designed for the people with ADRD and their caregivers together. Only during the meeting about “*Feelings about ADRD*” were people with ADRD and caregivers separated to express their feelings freely, and then reunited at the end. Active learning methods were used and the contents were adjusted according to the participants’ needs on the basis of continuous assessment.

2.6. Evaluation: To evaluate the impact of TPE on the people with ADRD and the caregivers, three types of tools were used: quantitative evaluation by standardized scales filled out before and after TPE, qualitative evaluation and educative evaluation.

For quantitative evaluation, the standardized scales used were the Hospital Anxiety and Depression scale (HAD) (7), the Quality of Life in Alzheimer’s Disease scale (QOL-AD) (8), and the Zarit Burden Inventory version 22 items (ZBI-22) (9, 10). Qualitative evaluation was based on attendance and a Satisfaction Questionnaire SQ filled out by the participants at the end of the session. Educative evaluation was based on interviews comparing the individual needs assessment before and after TPE.

Socio-demographic characteristics of participants were described by frequencies and percentages for qualitative variables and by means and standard deviation for continuous variables. To compare quantitative variables between before and after TPE on continuous data (HAD scores, QOL-AD scores, ZBI-22 scores), paired samples Wilcoxon tests were used. All analyses were performed using SPSS for Windows 25.0 (IBM Corp., Armonk, NY, USA). Level of significance was P value < 0.05.

3. RESULTS

3.1: TPE activity: From 2011 to 2017, twelve sessions of the ADRD TPE program took place. Three sessions were dedicated to PPA, one session was dedicated to PCA, four sessions were dedicated to FTLD and four sessions were dedicated to EOAD (Table 2).

3.1.1: Population: A total of 105 people (52 people with ADRD and 53 family caregivers) participated in the ADRD TPE program from 2011 to 2017. Globally, the

people with ADRD were aged from 45 to 80 years old with a mean age of 65.5 years. The PPA group was the oldest, on average 70.3 years old (59 to 80), whereas the EOAD was the youngest, on average 62.4 years old (52 to 66). The FTLD group was on average 66.1 years old (45 to 79); the PCA group was on average 64.5 years old (51 to 77). The people with ADRD were more often men than women (30 men versus 22 women). Only the EOAD group presented more women than men (11 versus 7).

Different socio-cultural backgrounds were represented amongst people with ADRD: 49% had elementary or secondary school education (level one = 6 to 9 years of schooling), 33% had completed secondary school (level two = 9 to 12 years) and 18% had university education (level three = over 12 years). The EOAD group was the less educated (61% level one; 22% level two; 17% level three), versus the FTLD group that was the most educated (38% level one; 31% level two; 31% level three).

Fifteen people with ADRD were working at the time of diagnosis of their ADRD (3 PPA, 2 PCA, 3 FTLD, and 7 EOAD); they all had stopped working at the time of TPE. Three people with ADRD had children living at home at the time of diagnosis (2 EOAD and 1 FTLD) and during TPE. All the people with ADRD were accompanied by their spouses and for one person, a second caregiver that was a child. Eighteen of the caregivers were working during the time of the TPE sessions.

3.1.2: Stages of ADRD: The delay between the first symptoms and the diagnosis was three years on average, with a wide range varying from less than one year to 13 years. The delay between the diagnosis and the TPE program was 1 to 4 years; in several cases, the TPE program took place the year the diagnosis was established. The average Mini-Mental State score was 18/30 for the EOAD groups (5/30 to 28/30), 23/30 for the FTLD groups (18/30 to 27/30). In the PPA groups, Mini-Mental State scores varied widely, from 2/30 to 28/30 depending on the severity of aphasia.

3.2: Individual educational assessment

The assessment was performed before TPE, individually for the people with ADRD based on an interview and questionnaires. The caregivers were also assessed individually with the same tools. During the interviews, the participants expressed spontaneously their needs and requests, whereas questionnaires were used to collect data on predetermined information items.

The assessment of individual educational needs was used as baseline to guide the TPE program and at the end of the program to determine whether the participant's skills had progressed. Each participant could express one or more requests (Figure 2).

Family caregivers generally expressed more requests than people with ADRD, who could have reduced capacities to express themselves due to their disorders. “*Understand the disease and its consequences*”, as well as “*Maintain good relationships*”, especially with their spouse, were the main requests of people with ADRD (45% and 42% respectively) and of the family caregivers (60% and 76%). “*Adapt lifestyle*” (76% caregivers, 27% people with ADRD) and “*Prevent complications*” (60% caregivers, 36% people with ADRD) were mainly requested by caregivers. Spontaneously, participants expressed less requests about “*Getting help and support*” (41% caregivers, 24% people with ADRD), about “*Managing situations*” (38% caregivers, 21% people with ADRD) or about “*Communication*” (38% caregivers, 15% people with ADRD): referring to their experience, the TPE professionals introduced these themes into the program.

3.3. Evaluation

Quantitative evaluation using standardized tests before the TPE program proved stressful for the people with ADRD and the caregivers, and after the TPE program, symptoms of ADRD had progressed. 85 participants (81%) filled out the scales (42 people with ADRD and 43 caregivers); only 26 participants (10 people with ADRD and 16 caregivers) succeeded in completing correctly all the scales before and after TPE (Figure 3).

Before TPE, HAD scales (N= 62) showed average levels of anxiety and low depression levels in both people with ADRD (8.2 ± 4.7 anxiety and 6.2 ± 3.2 depression) and caregivers (9.0 ± 5.1 anxiety and 6.6 ± 4.2 depression); after TPE (N = 26) there were no significant changes in HAD scales in people with ADRD ($p=0.31$ and $p=0.88$) or in caregivers ($p=0.17$ and $p=0.12$) even though the symptoms and the disorders had progressed.

Quality of life (QOL-AD) before TPE (N = 46) was similar for people with ADRD and caregivers (35 ± 4.3 and 32.7 ± 5.5). After TPE (N = 29), quality of life had decreased significantly for caregivers (32.7 ± 5.5 reduced to 29.7 ± 5.4 ; $p = 0.04$), especially concerning their financial situation (*item 12*: 2.8 ± 0.68 reduced to 2.3 ± 0.94 ; $p = 0.04$), whereas quality of life did not change for people with ADRD (35.4 ± 4.3 to 35.2 ± 6.1 ; $p = 0.69$).

Before TPE, caregivers (N = 32) expressed a mild burden (ZBI-22 = 35); after TPE (N = 16), burden was similar except for the item “*Do you feel that you will be unable to take care of your relative much longer?*” which had a tendency to decrease (p=0.05).

Qualitative evaluation was performed by following attendance and participation during the TPE session and by a Satisfaction Questionnaire completed at the end of the session TPE by the participants.

Attendance was incomplete for eight people with ADRD and their nine caregivers (16%) for different reasons. Two couples did not wish to continue after the first meeting, so follow-up was continued individually. Five couples discontinued TPE because the person with ADRD was admitted to a nursing-home during the session. One couple interrupted TPE because the person with ADRD developed breast cancer that needed urgent treatment. In another case, the caregiver interrupted TPE because of stroke, but the person with ADRD continued to participate.

Participation evolved during the TPE session. There was always an important emotional strain during the first meeting, when the people with ADRD and their caregivers discovered other people living with the same disease. It was important to let them all express themselves. The meeting concluded with an outline of the similarities between people with ADRD, between caregivers, and between all participants to help create cohesion in the group. As the session went on, the participants relaxed and began to look forward to seeing each other from one meeting to another. Friendships were formed and some couples exchanged phone numbers and continued to see each other once the TPE session was over.

The Satisfaction Questionnaire revealed that one of the strong points of the TPE program was meeting other people with ADRD and caregivers living with the same disease. The participants also reported better understanding of the disease and its consequences, and better knowledge about help and support systems.

Educative evaluation: An interview at the end of the TPE session took place individually for people with ADRD and for family caregivers with their referent neuropsychologist. The evaluation for people with ADRD’s mainly showed progress in “*Understanding the disease*”, and in “*Maintaining a good relationship*”. For caregivers, progress was noted in all requests, even those not expressed spontaneously, such as “*Getting Help and Support*” and “*Communication*”.

4. Discussion:

People with ADRD are most often discredited because of cognitive decline, and the caregiver becomes the main discussion partner for professionals. Many programs and other facilities have been conceived and organized to help caregivers, the common belief being that when the caregiver gets support, the person with ADRD is indirectly getting care and “being better/not getting worse”, especially when behavioral symptoms occur (5). Participation of people with ADRD in these interventions is generally found to be beneficial (11). TPE is different from psychosocial interventions because the person with ADRD is the center of attention, and the objective is not so much to stimulate his/her capacities rather than to give the opportunity to learn about his/her disease and to adapt to the situation. TPE aims to enable people with chronic disease to acquire and maintain abilities to optimally manage their lives with their disease. It is therefore a patient-centered continuous process: it includes organized awareness, information, self-care learning and psychosocial support regarding the different aspects such as the disease, prescribed treatment and care, organizational information, and behavior related to health and illness (1).

Following progress in biomarkers, ADRD diagnosis can be performed in very early stages of the disease, where people with ADRD usually have preserved capacities to participate in discussions and decisions. It is then very important to offer TPE, so that they can understand and accept the disease and its consequences, and learn to manage their lives with the disease as long as they can. This early stage is also favorable for professionals to inform people with ADRD and know about their decisions for the future, as well as to get their consent for research (12).

The participation of the main caregiver in the TPE program is necessary because the relationship between the person with ADRD and the caregiver is the core part of their life, and maintaining the quality of this relationship is one of their main concerns (Figure 2). In several cases, the TPE professionals realized that the disease had never been discussed in the family circle, and so TPE meetings were opportunities for the person with ADRD and their caregiver to exchange about their feelings. Finally, as the disease progressed, the caregiver progressively had to take on more activities and responsibilities: TPE allows the caregiver to be armed for this eventuality, and to be aware of the person with ADRD’s wishes.

It is interesting to note that people with different types of ADRD benefited from TPE. The first sessions (2011-2013) were designed for groups of people with focal deficits due to PPA or PCA. Since 2014, the TPE team developed sessions adapted to people with EOAD, who usually have very good insight about their situation and many questions to ask at the beginning of their disease. TPE in advanced stages can still be profitable to people with EOAD and their family caregivers, thanks to preserved social skills that allow good participation, which is very important for self-esteem. For people with FTLD, the TPE team was worried about behavior problems, so in 2014 the first FTLD session was designed with separate meetings for caregivers and for patients. As soon as the first meeting started, it became obvious that people with FTLD wanted to be with their caregivers. Moreover, their behavior problems did not disrupt the TPE meetings: people with FTLD suffering from apathy benefited from the stimulation and those with disinhibition brought a welcome sense of humor to the meetings. Since 2015, the TPE meetings address the people with FTLD and their caregivers together.

Initial levels of anxiety and depression were low in the study population. After TPE levels of anxiety and depression did not increase even though the people with ADRD's disorders had progressed with time, so TPE probably had a favorable effect on preventing anxiety and depression in both people with ADRD and their caregivers. While quality of life has been reported to increase following TPE (13), this was not the case in our experience. Indeed, the caregivers' quality of life decreased significantly, mainly because of financial worries (item 12). The tendency to decrease the burden in the item ZBI-22 "*Do you feel that you will be unable to take care of your relative much longer?*" may reflect better self confidence of the caregivers, which is an interesting outcome for TPE. Recommendations in TPE practice (1) consider that individual educative assessment before and after TPE is the best measure of the effect of TPE. In this experience, general satisfaction of the participants was very good. After TPE, participants reported better understanding of the disease and its consequences as well as new professional and/or friendly contacts for further help.

Sessions of TPE are composed of scheduled meetings with planned progressive themes. From the requests expressed by people with ADRD and the caregivers at initial assessment (Table 2), the TPE team developed the targets for TPE in ADRD (Table 3). These targets can be used for people with ADRD and for their caregivers. The delay between the meetings is useful to let people with ADRD and caregivers try new attitudes

or actions. However this experience showed that as the disease progresses, people with ADRD and caregivers tend to drop out or are unable to participate. Our revised TPE program is shortened to six sessions (Table 4). Successful TPE for people with ADRD is a question of good timing: not too late, not too long.

5. Strength and weakness:

This report is an original clinical experience that addressed a significant number of cases of rare pathologies, recruited over the years by a single CRMC. Moreover, in absence of curative medication there is increasing interest in studies about non-pharmaceutical care of people with ADRD and their caregivers. Even though authorization by an ethical committee was not obtained (because not mandatory at the time), ethical considerations were met because written consent was collected from all participants, people with ADRD and caregivers.

One of the limits of this experience is the absence of a control group, because it is difficult to organize in rare pathologies, and because the people with ADRD who refused to participate were considered clinically different from those included due to more pronounced anosognosia. The main weakness of this clinical experience is linked to the few measures completed before and after the TPE program, due mainly to progressive worsening of symptoms that is the characteristic feature of ADRD: because of this, the TPE team decided to reduce the number of meetings from eight to six.

6. Conclusions

TPE is designed to help patients with chronic disease and their families to understand the disease, manage their situation and cooperate with healthcare providers, so they can maintain or improve their quality of life. The ongoing experience of TPE at the CRMC demonstrates that TPE is possible to achieve for people with a wide variety of ADRDs and their family caregivers, especially in early stages of the disease. TPE can prevent anxiety and depression in people with ADRD and in caregivers, and may reduce the burden of caregivers. The general guidelines outlined in this paper should help more professionals engage in this activity and offer TPE to people with ADRD as soon as they are diagnosed. Because there is currently no curative treatment for ADRD, TPE is an ethical necessity. As more memory centers engage in TPE, it would be very interesting to

conduct a multiple-center study to increase the power of the experience and define the best indicators and the best methods for TPE for people with ADRD and their caregivers.

Disclosure of interest

The authors declare no conflict of interest

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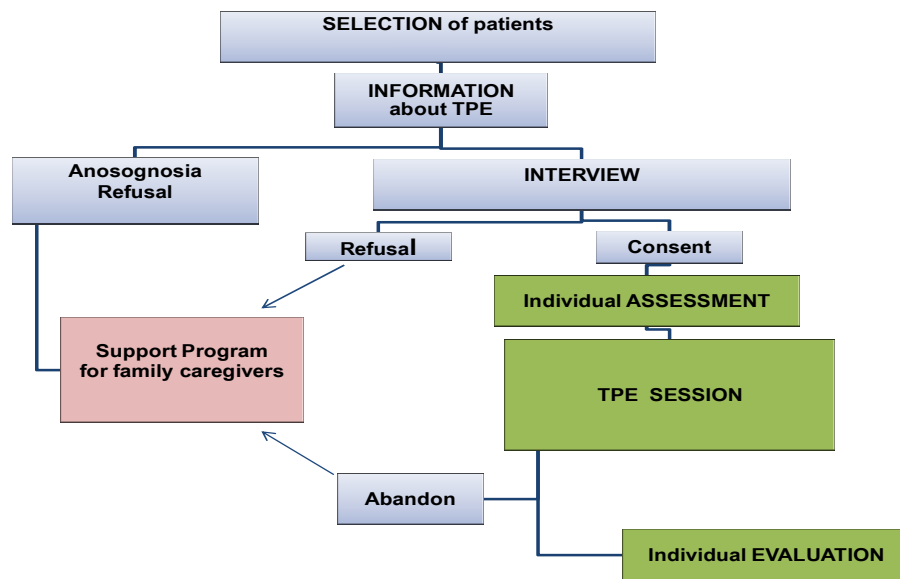


Figure 1: Selection of TPE participants

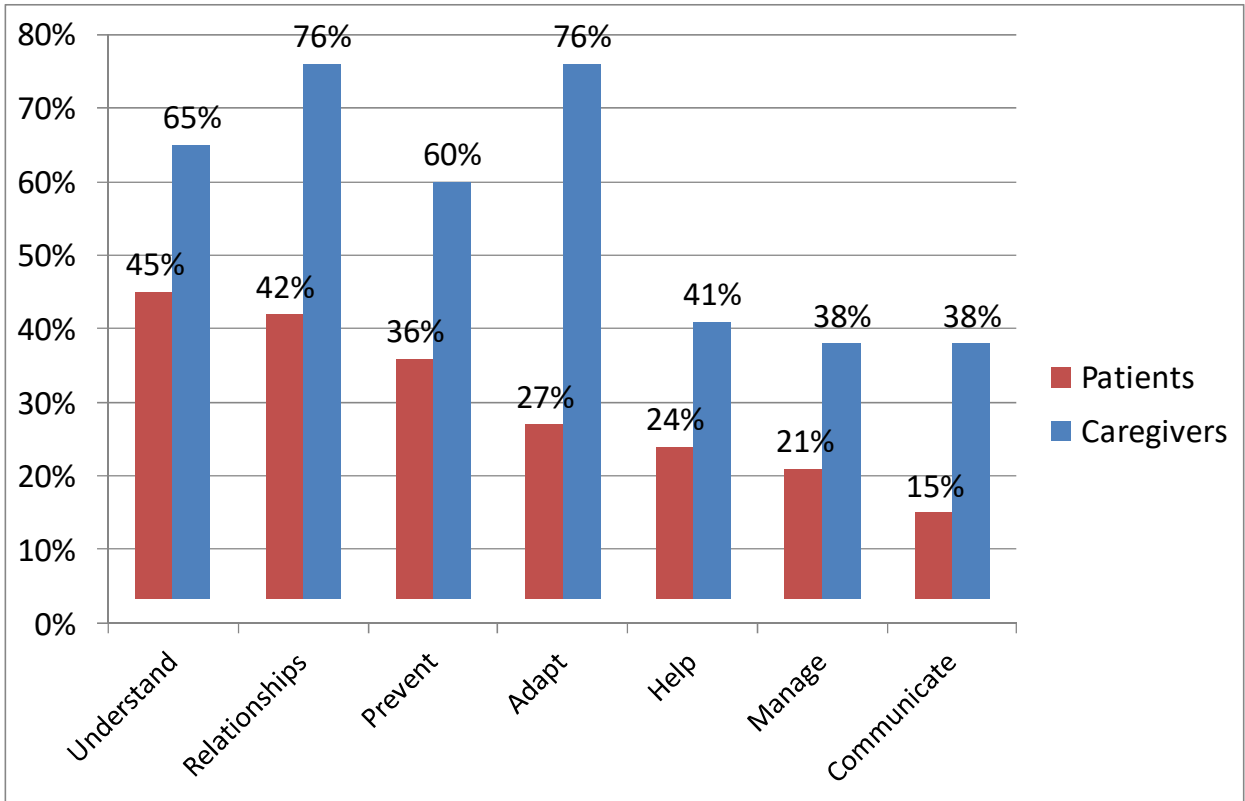


Figure 2: Requests at initial assessment (based on 85 interviews)

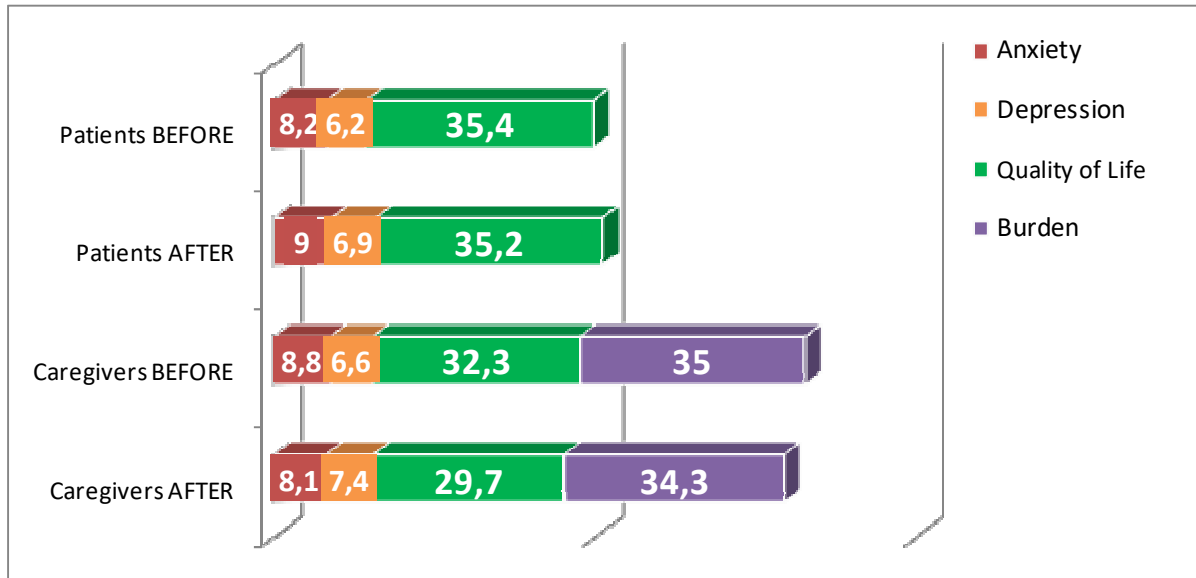


Figure 3: Quantitative evaluation before and after TPE

Table 1: General Framework of the ADRD TPE program

MEETINGS	THEME	SKILLS METHODS	PROFESSIONALS
Individual Interview	Information and written consent Assessment of educational needs	BASELINE EVALUATION <i>Standardized scales and Questionnaires</i>	Neuropsychologist = reference of the group
Meeting 1	Introduction	CREATE GROUP COHESION	Neuropsychologist TPE team
Meeting 2	ADRD and the brain	UNDERSTAND- PREVENT	Neuropsychologist Memory Doctor (Neurologist, Psychiatrist or Geriatrician)
Meeting 3	Cognitive disorders due to ADRD	UNDERSTAND – ADAPT	Neuropsychologist Psychologist or nurse
Meeting 4	Emotional changes due to ADRD and communication skills	MAINTAIN RELATIONSHIPS and COMMUNICATION SKILLS –ADAPT	Neuropsychologist Psychologist or nurse
Meeting 5	Help and support systems	MANAGE- GET HELP	Neuropsychologist Social Worker
Meeting 6	Communication skills	RELATIONSHIPS–COMMUNICATION	Neuropsychologist Speech therapist or nurse
Meeting 7	Feelings about ADRD	ADAPT-COMMUNICATION	Neuropsychologist Psychologist or nurse
Meeting 8	Continuing projects and activities with ADRD	PREVENT – ADAPT	Neuropsychologist TPE team
Individual Interview	Assessment of educational progress	FINAL EVALUATION <i>Standardized scales and Questionnaires</i>	Neuropsychologist = reference of the group

Table 2: TPE sessions and participants from 2011 to 2017

ADRD	2011	2012	2013	2014	2015	2016	2017	Total 2011- 2017
PCA				4 patients 4 caregivers				8
PPA	5 patients 5 caregivers	5 patients 5 caregivers	4 patients 4 caregivers					28
FTLD				4 patients 5 caregivers	4 patients 4 caregivers	8 patients 8 caregivers (2 GROUPS)		33
EOAD				5 patients 5 caregivers	4 patients 4 caregivers		9 patients 9 caregivers (2 GROUPS)	36
Total	10	10	8	27	16	16	18	105

Table 3: Suggested Education TARGETS for ADRD

EDUCATION TARGETS for People with ADRD and Caregivers	
SELF MANAGEMENT SKILLS	
Understand and be able to explain	<ul style="list-style-type: none"> - the disease, the impact on the brain - the signs and symptoms - the evolution - the effect of the treatment and care
Maintain good relationships	<ul style="list-style-type: none"> - with the spouse - within the family circle - be aware of the impact of the disease on the family and on work or social life
Self care and management	<ul style="list-style-type: none"> - take appropriate medication - monitor weight /adapt food and diet - keep adapted social activities - practice sport and/or adapted physical activities - adapt environment
Prevent complications of the disease	<ul style="list-style-type: none"> - be aware of the risk of errors of medication intake - be aware of the risk for driving -be aware of the risk of swallowing difficulties - be aware of the risk of getting lost
Get support and help	<ul style="list-style-type: none"> - know about financial support - know about respite services - know about legal protection - accept help and assistance
COPING and ADAPTATION SKILLS	
Adapt emotions and feelings	<ul style="list-style-type: none"> - reduce fear and self stigma - improve self-esteem and sense of self-reliability - accept the consequences of the disease - have adapted projects - accept to plan ahead
Develop communication skills	<ul style="list-style-type: none"> - express feelings and emotions - communicate with family, with friends - communicate with professionals

Table 4: Revised session of the ADRD TPE program

MEETINGS	THEME	SKILLS METHODS	TRAINED TPE PROFESSIONALS
Individual Interview	Information and written consent Assessment of educational needs	BASELINE EVALUATION <i>Standardized scales and Questionnaires</i>	Neuropsychologist = reference of the group
Meeting 1	Introduction	CREATE GROUP COHESION <i>Round Table</i> <i>Outline similarities</i>	Neuropsychologist TPE team
Meeting 2	ADRD and the brain	UNDERSTAND- PREVENT <i>Questionnaire “ NAME YOUR DISORDER”</i> <i>Prevention Cards</i>	Neuropsychologist Memory Doctor (Neurologist, Psychiatrist or Geriatrician)
Meeting 3	Cognitive disorders due to ADRD	UNDERSTAND – ADAPT <i>Symptom cards</i>	Neuropsychologist Psychologist or nurse
Meeting 4	Emotional changes due to ADRD and communication skills	MAINTAIN RELATIONSHIPS and COMMUNICATION SKILLS –ADAPT <i>Symptom cards and Communication game(s)</i>	Neuropsychologist Psychologist or nurse
Meeting 5	Feelings about ADRD	ADAPT-COMMUNICATION <i>Round tables (separate for people with ADRD and for caregivers)</i>	Neuropsychologist Psychologist or nurse
Meeting 6	Continuing projects and activities with ADRD	ADAPT – MANAGE- GET HELP <i>Questionnaire about dysfunctional statements</i> <i>Discuss help and support systems</i>	Neuropsychologist TPE team
Individual Interview	Assessment of educational progress	FINAL EVALUATION <i>Standardized scales and Questionnaires</i>	Neuropsychologist = reference of the group