

## Occupational therapy in special respite care: a new multicomponent model for challenging behavior in people with dementia

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### Abstract

People with dementia experience a cognitive and functional decline and besides Behavioral and Psychological Symptoms (BPSD). BPSD represent the main cause of the dramatic deterioration in the quality of life and stress for patients and their families. BPSD can benefit from psychosocial and environment approach; in particular the *tailor made* treatment has proved the best results in literature. The intervention of Occupational Therapist (OT) at home (CotiD-Method) and in Nursing Home on elderly people with moderate dementia can improve BPSD. OT is the trigger figure that can understand the intricate relationship between person, environment and occupation that is required for successful task performance. Our prospective cohort study analyzed a sample of 14 People (aged 82±5.88) With moderate-severe (MMSE mean 9.29/30 sd=6.88) Dementia (PWD) and severe BPSD (NPI=31.79±7.62) in a Temporary Special Respite Care (SRC) in Modena. We test how a multi-professional approach and a Personal Care Planning including occupational therapy could be effective in challenging behaviors. The method includes formal and informal caregivers reflecting CotiD method.

Our results show that occupational therapy can significantly improve BPSD and quality con life in PWD. The multiprofessional approach permitted to reduce number of psychotropic drugs and also falls. The general positive mood reflects on professionals working in SRC in the sense of improvement,even if not significantly, of psychological load and personal fulfillment. In the same way even formal caregivers

who assist PWD at home, learned skills in managing the exacerbation of BPSD.

### Introduction

The elderly population is constantly growing in all countries as a consequence of the constant increase of life expectancy for both men and women, in particular life expectancy at birth of the European population is among the highest in the world (80.0 years) Today it is estimated that 46.8 millions of people in the world are affected by a form of dementia (in Italy over 1 million and 200 thousand), a number destined to double every 20 years to reach 74.7 million people in 2030. It has been estimated that every year the total number of new cases of dementia is almost 7.7 million, which implies a new case every 4 seconds.<sup>1</sup>

It is evident that the significant global prevalence, the economic impact of dementia on communities and on families make dementia a significant challenge for public health. The Italian National Dementia Plan (PND)<sup>2</sup> document was formulated by the Ministry of Health for the promotion and improvement of quality and the appropriateness of welfare interventions in the dementia sector.

Among these, dementia is one of the prevalent as well as one of the major causes of disability and afflicts a considerable number of elderly people in both developed and developing countries with a consequent significant social-health impact.<sup>1</sup> Most people with dementia - PWD, people with dementia - during the disease manifest symptoms and behavioral disorders - BPSD, Behavioral and Psychological Symptoms of Dementia - and this is the main cause of institutionalization, often earlier than the disease phase, or hospital admission, often inappropriate, with negative consequences for the patient and the family. In addition to the cognitive and functional decline related to dementia, the BPSD represent the main cause of the dramatic deterioration in the quality of life for patients and their families. Indeed, caregiver is subjected to a gap between amount of requests and the available resources that lead to *burn out*, psychological syndrome characterized by emotional exhaustion, depersonalization, and lack of sense of personal accomplishment.<sup>3,4</sup>

Considering the low efficacy of drugs and their many side effects, BPSD can benefit from psychosocial and environment approach. In particular the *tailor made* treatment has proved the best results in literature.

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The Kitwood's experience, the most recognized *Person Centred Care* model available, inspired and helped us to build our study.<sup>5</sup> It is also important to teach the caregiver the right methods for an appropriate approach to BPSD in order to reduce agitation, stress in caregiving and improve mood.<sup>6</sup>

Psychosocial intervention that people with dementia (PWD) can benefit are: cognitive rehabilitation, occupational therapy, music therapy, multisensory interventions, person center care and family caregiver training. Occupational therapist has a strategic role in identifying significant occupation in mild moderate dementia at home resulting in improvement of quality of life in people with dementia (PWD) and their caregiver<sup>6-8</sup> In particular CoTID method (*Community occupation therapy, Graff 2006*) acts for one of the most effective psychosocial intervention. Occupational Therapy improves quality of life and mood of people with mild-moderate dementia and their caregivers at home (*Community occupation therapy Graff 2006*). Literature shows that the intervention of OT at home on elderly people with moderate dementia and BPSD improves the quality of life for them and their families, by reducing the behavioral disorders and the stress of the caregivers. In particular a Tailored Activity Program has demonstrated to be effective.<sup>9</sup>

On the other hand few studies investigate the role of OT in the administration of BPSD in elderly with institutionalized dementia. Among the most effective models the DICE approach represents a multi-professional model that involves health figures and social assistance in the integrated management of BPSD.<sup>10</sup>

Respite Care was born as a caregiver

different support to reduce physical and social load and to provide individualized treatments linked with other social and health services.<sup>11</sup> Literature shows insufficient and inconsistent proof of any benefit of this in regard to caregivers stress and sense of competence, neither it seems to postpone institutionalization.<sup>12</sup>

In Modena and Emilia Romagna Region two types of different Respite Care coexist: Specialized Respite Care (SRC) for people with moderate-severe dementia associated with severe BPSD and Traditional Respite Care in which cognitive or physical impaired older people without severe BPSD are included.<sup>13</sup>

The aim of SRC is preserve cognitive and functional abilities, reduce BPSD with pharmacological and/or non-pharmacological approach, train caregiver to approach and prevent BPSD, postpone institutionalization and facilitate the transfer to a Traditional Respite Care.

The Modena's SRC is localized inside the *IX Gennaio Nursing Home* and it is a special units (20 beds for people with a diagnosis of probable Alzheimer's disease or a related dementia) that provides an organized, continuous 24-hour-per-day program of supervision, care and services that promotes the social, physical and mental well-being of residents and meets all admission criteria applicable for management of BPSD. The special care unit guarantees (within a prosthetic environment) a various type of therapeutic activities than can improve a resident's eating or sleeping patterns; less wandering, restlessness, or anxiety; improve socialization or cooperation; delay deterioration of skills; and improve behavior management. Therapeutic activities have been designed to meet the resident's current needs and to avoid or reduce the use of psychotropic drugs and physical restraints.

The SRC team is composed of geriatrician, professionals, occupational therapist, psychologist, expert, entertainer.

We know that Occupational Therapist intervention can reduce BPSD in particular Agitation.<sup>6</sup> The involvement of the occupational therapist within the routine activities of the SRC is important both for the training to formal and informal caregivers on this approach, for the communication towards to patient suffering from dementia. Moreover occupation therapy is shown to have effective results in the management of Dementias.<sup>7</sup> Among the occupational therapy models to which we are inspired, the CoTiD method is the most influential one<sup>8</sup> even if it has never been declined on a population of elderly people with moderate-severe dementia and severe behavioral disorders within a residential setting.

## Objective

This prospective Cohort study wants to observe benefit of a multi-professional model (*Occupational Therapist, Geriatrician, Social-welfare worker*) in management of challenging behavior in a small sample of PWD and severe BPSD. It's consists of the development of a Personalized Care Plan (PCP) through the collection of biographical history and history of significant activities, analysis of needs, exclusion of causes triggering the BPSD and the formulation of a project of occupational therapy with CoTiD methodology with involvement of the formal caregiver.

Main outcome was to reduce the intensity and/or frequency of behavioral disorders. Other secondary outcomes were: Improve quality of life in PWD (reduction in the number of drugs and reduce the number of falls, reduce care stress of the informal caregiver through training on the correct communication-relationship with the elderly with dementia and behavioral symptom management and reduce the care stress of the formal caregiver through the involvement in the occupational activities with the elderly person).

## Materials and Methods

OT interventions have been focused on environmental and organizational changes according to the model of Moyra Jones.<sup>14</sup> The environmental changes aimed to make the Nursing Home more familiar, traditional and *similar to home*, to give the idea of a quiet environment and to remove the idea of institutionalization and/or sanitation of the center.

Then a staff training regarding to identification and analysis of BPSD and Person Center Care approach of Kitwood has been organized.

Organizational changes consisted on developing different staff work plans, which included individual/group recreational activity time OT has a coordinative role and supports the individual/group activities, which are performed in collaboration with recreational staff.

PCP has been planned for each client. Demographic, cognitive, clinical, functional and behavioral data has been gathered before PCP (T0) and after three months (T1). The multiprofessional PCP supports the exclusion of clinical problems, which could potentially trigger BPSD, drugs review, client story and client's needs, formal and informal caregiver's story and OT suggestions. The OT strategy is adapted to cognitive impairment and life story of each patient. In Home Setting the OT interven-

tion takes as reference the Community Occupational Therapy in dementia<sup>8</sup> and provides for an active involvement of informal family members and caregivers.

## Inclusion criteria

- Seniors >65 years suffering from dementia, according to the criteria of DSM V, moderate to severe: cognitive impairment tested with MMSE<sup>15</sup> (Mini Mental State Examination) between 20 and 0/30.
  - BPSD measured with scale NPI<sup>16</sup> (UCLA - Neuropsychiatric Inventory) >24/144 with impact on client's life and on the caregiver's relationship and difficult home management.
  - The study population had to have low comorbidity<sup>17</sup> (CIRS <3).
  - Walking autonomy.
  - The informal and formal Caregiver available for PCP and project participation.
- Preliminary evaluations at T0 of our sample included measures on the patient, the formal and informal caregiver. The same measures were reevaluated 3-month later (T1).

## Patient rating

- Age, Comorbidity (CIRS), number of total drugs and psychotropic, number of drops in the last 3 months.
- Cognitive level (MMSE) corrected for age and schooling and the degree of Dementia disease (Dementia Rating Scale, CDR).<sup>18</sup>
- The type and severity of affective disorders (*Cornell Depression Scale*)<sup>19</sup> and behavioral disorders<sup>16</sup> (*Neuropsychiatric inventory, NPI*).
- The perception of quality of life<sup>20</sup> (*QuoLAD*).

## Evaluation of the formal caregiver

- Age, education, years of work experience with users suffering from dementia, sex.
- Level of stress and burnout<sup>21</sup> (Maslach questionnaire.) from this test have extrapolated the values of burnout emotional exhaustion (EE), depersonalization (DP) and sense of competence (PA).
- MSL EE: Syndrome from emotional exhaustion in work (chronic fatigue, depressive SDR, anxious...) that fades after work.
- MSL DP: depersonalization, dehumanization, lack of empathy. Concerns the excessive detachment, cynicism and negative attitude towards the client and colleagues, guilt.
- MSL PA: Reduced awareness of your abilities; it is the consequence of the

first two burnout. Pessimism, feeling of inability to deal with problems, demotivation before difficulties.

- Assessment of the sense of competence and satisfaction with the objectives set during PCP measured with COPM<sup>22</sup> (Canadian Occupational Performance Measure).

#### Assessment of the informal caregiver

- Age, gender, type of kinship with the user, years of illness and cohabitation or not.
- Level of welfare stress<sup>23</sup> (Zarit Burden Inventory) and sense of Competence Questionnaire<sup>24</sup> (SCQ).
- Assessment of the sense of competence and satisfaction with the objectives set during PCP (COPM).

The experimental project, began in October 2015 and ended in March 2016.

#### Descriptive analysis of the sample

Patients included in the study were 14 (F:M=7:7) and had an average age of 82±5.88.

Cognitive status (MMSE mean 9.29/30 sd=6.88) and severity of dementia (CDR mean =3) at the baseline were moderate to severe. Comorbidity was low (CIRS mean =1.3 sd 1.2). Only two subjects felt at home in the previous 3 months. Number of medications taken were 5.36 sd 2.34. All patients had been treated with at least one psychoactive drug.

The four professionals had an average age of 56.6 years (DS 7.55), with a 8.75 year education (DS=1.5) and work experience with people with dementia of 19.5 years (DS=7.85).

Six major relatives/assistants (M:F=1:5) agreed to participate in the project and completed the tests for stress (Zarit) and Sense of Competence Questionnaire (SCQ), both at baseline and at T0. Two were living with the patients as they were their partners (17%, age 58 years (DS 3.29), the others were sons/daughters (83%). They have been involved in patient care since the first diagnosis (76 months, DS 28.899).

age (NPI to T0=31.79±7.62) as depressive symptoms close to clinical relevance (Cornell Depression Scale T0=8.57±2.68 - CUT OFF=9) and low quality of life perceived by relatives (QOLAD T0=24.25±4.65 - max 52).

After treatment with the occupational therapy structured in the PCP we observed a significant reduction of BPSD as total score NPI (t 4.6 Sig. 0.001) and an improvement of depressive symptoms at Cornell's Depression Scale (t 5.85 Sig. 0.000).

Considering the only 6 relatives available for evaluation at the T1 follow-up we observed an improvement of quality of life of the patient perceived by relatives (QoLAD) even if this result has not been achieved statistical significance, probably due to sample size. Furthermore, a reduction in the use of antipsychotic drugs (f 2.09 Sig. 0.040) and falls compared to 3 months before treatment (t 2.503 Sig 0.028). Only one patient left the study due to hospitalization (Table 1).

Among the psychopathological groups of NPI we found that the behavioral disorders that have benefited most from the treatment with occupational therapy were agitation/aggression (t 2.987, Sig. 0.011) and

aberrant motor activity (t 2.363, Sig. 0.036) (Figure 1).

#### Stress of health operators at T0 and T1

All health professionals took part in the project and assisted patients. Burnout measures through the Maslach data, before the educational program and the environmental changes, have shown a moderate-to-severe discomfort and burnout between the subscales of Maslach: depersonalization [T0MSL DP=12.00 (DS 5.94) severe burnout] and awareness of personal competence [T0MSL PA=36.75 (DS 2.06) moderate burnout]; the cause of burnout of emotional exhaustion has been shown to be mild (T0MSL EE=14.25, DS 9.22).

After the project and the environmental changes previously exposed, the stress decreased in all three domains: in particular, the burnout due to depersonalization that went from severe to moderate decreased (Figure 2). Due to the small sample size and the presence of interfering covariate (education and work experience of health workers) it was not possible to perform a meaningful statistical analysis.

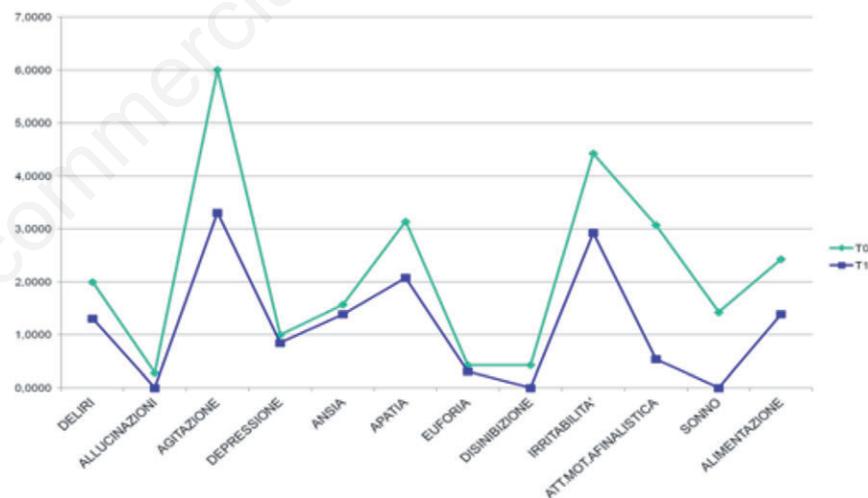


Figure 1. Single cluster NPI mean at T0 and T1.

## Results

The data were analyzed with IBM SPSS. Statistical significance was set at  $p < 0.05$ . T-test of coupled samples it has been used for continuous variables with normal distribution.

#### Results in people with dementia in T0 and T1

Our subjects presented at baseline (T0) serious behavioral disorders difficult to man-

Table 1. Means and standard deviation of the sample measurement at T0 and T1.

	T0 mean (SD)	T1 mean (SD)	Sig.
NPI	26.46 (11.52)	13.85 (7.66)	0.001
N° neuroleptic	0.46 (0.52)	0.15 (0.38)	0.040
N° falls	0.54 (0.78)	0.00 (0.00)	0.028
Cornell	8.5 (2.68)	3.8 (3.05)	0.000
QolAD	24.25 (4.65)	31.17 (8.35)	n.s.

### Stress in informal/relatives and sense of competency at T0 and T1

The 6 relatives/caregivers who participated in the project of occupational therapy at home presented at baseline T0 stress level close to clinical relevance: T0 Zarit=34.00 sd 12.633 (cut-off >36 with necessity of health assistance) although with a good sense of competence T0 (SCQ=68.5 sd 7.66). After treatment with the OT we observed a decrease in caregiver-burden and improvement of sense of competence even if it was not possible to reach statistical significance for sample sizes (Figure 3).

chological load and personal fulfillment. In the same way even formal caregivers who assist PWD at home, learned skills in managing the exacerbation of BPSD.

The limits of the study are the small sample and the absence of a control group. We also found difficulties in the informal caregiver involvement in OT treatment at home, probably due to the high level of distress collected.

This study wanted to suggest a new multiprofessional Person Centered Care Model, including OT as a trigger figure, to

solve behavioral problems in PWD and help formal and informal caregivers to manage and have skills in problem solving against BPSD. This aid could reduce burn out in caring, promote home-stay and postpone institutionalization. We hope in the future to evaluate this program in a large group of PWD and their caregiver in order to highlight more significant and generalizing results. Moreover we hope in implementation of Occupational Therapists in the working team along with geriatrician, nurses and professionals in SRC.

### Discussion and Conclusions

BPSD are the consequence of interacting factors both internal and external to persons with dementia, they are among the most significant challenges in dementia care and remain under- or mistreated. Psychotropic medications have a low risk-benefit profiles, moreover have not impact in some of the most frequently occurring symptoms that are most distressing to families and that trigger hospitalizations or nursing home placement. Occupational therapists possess the expertise in understanding the intricate relationship between person, environment and occupation that is required for successful task performance. The role of the occupational therapist is to find the best or just-right fit between the environmental and task demands, and the cognitive ability of the patient. A patient-centered plan will consider meaningful and realistic occupations for the person with dementia, strategies for maintaining the person's safety, as well as strategies that enhance the caregiver's support while easing some of the stress of caregiving.

Despite the small sample, our experience in occupational therapy in SRC shows that a multi-professional approach could be effective in challenging behaviors in PWD thanks to a Personal Care Planning.

Involving people with dementia in meaningful and graduated activities can be an effective method to respond to unsatisfied needs that PWD might express as BPSD.

Regarding the main outcome we detected a significant improvement in BPSD, in particular in cluster of agitation, aggression, wandering and aberrant motor behavior. This result was registered even in reduction numbers of used psychoactive drugs. The general quality of life for PWD improved and reduced falls. The general positive mood reflects on professionals working in SRC in the sense of improvement of psy-

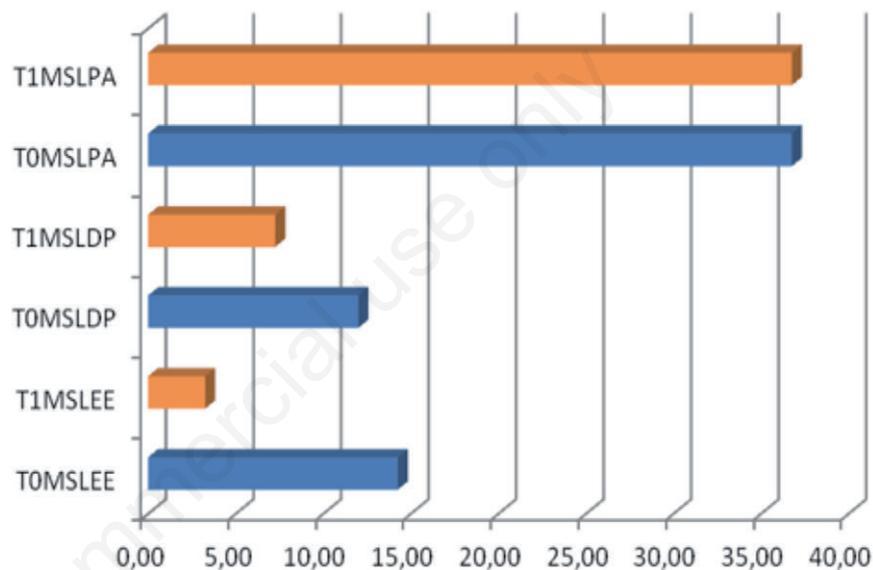


Figure 2. mean in sub scale of Maslach EE (emotional exestuation), DP (depersonalization), PA (personal achievement) at T0 and T1.

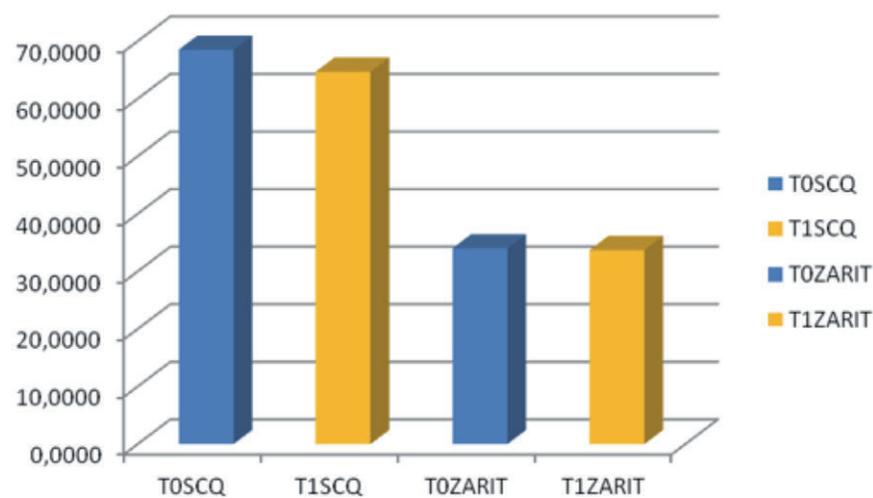


Figure 3. Mean in informal caregiver stress (Zarit) and sense of competence (SCQ) in management of BPSD at T0 and T1.

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