

**SUPPORT SYSTEMS**  
**FOR THE BEHAVIOURAL & PSYCHOLOGICAL SYMPTOMS OF DEMENTIA**  
*A "3D VIEW" ALL ALONG THE PATIENT PATHWAY*



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*\* Behavioural & Psychological Symptoms of Dementia*

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The behavioural and psychological symptoms of dementia (BPSD) originate from multiple sources, with the main source being degenerative processes caused by brain disease. Other sources include concomitant psychological or psychiatric conditions, like depression or psychoses, and environmental influences which may be strongly associated to an underlying diagnosis of a disease causing dementia. Since dementia is more prevalent in older persons than in younger ones, somatic illnesses that do not directly relate to dementia are also common. For example, such diseases include cardiovascular diseases, asthma and chronic obstructive pulmonary disease, diabetes mellitus or osteoarthritis. Additionally, common conditions which might be a factor in BPSD are pain, immobility, malnutrition, and incontinence. BPSD may also originate from a person's erroneous interpretation of his or her surroundings which can occur either with or without the loss of senses such as eyesight or hearing, or even balance. In addition, human emotions such as frustration, worry, sorrow or need of company or love, may play a role.

In addition to the cognitive and functional declines caused by Alzheimer's disease and Related Disorders, BPSD represent the main causes of a dramatic impairment of quality of life among people living with dementia and their carers, as well as the principal cause of subsequent institutionalisation. Different manifestations of BPSD may present at different stages of Alzheimer's disease. Specifically, anxiety, depression and apathy are often observed at mild stages of the disease, whereas aberrant motor behaviour and resisting care and help tend to occur at moderate to severe stages. Still other manifestations may occur at all stages of the disease, and this category includes agitation and aggressiveness, hallucinations, delusions, sleep and appetite disorders. Since pharmacological interventions are still far from efficient and are not well-tolerated, a non pharmacological strategy for treating BPSD appears to be crucial for both the prevention of such symptoms and their care.

The aim of this work has been to summarise the existing knowledge on support systems for BPSD. This included conducting a literature search on articles covering all non pharmacological and pharmacological strategies for BPSD, and identifying outstanding projects in Europe in order to promote best practices and to propose recommendations.

With the objective of proposing operational recommendations, ALCOVE has classified support systems for BPSD into three types or dimensions which are described in this chapter: **structures and care organisations** (first dimension) which are fully or partially dedicated to treating BPSD. These include ambulatory, hospital or nursing home settings, which provide a physical environment where pharmacological, psychosocial and other non pharmacological interventions may be applied. The second dimension involves these **Individualised patient and family carer interventions** and the third dimension involves **workforce & skills** which includes educational programmes designed for professional or informal carers.

## STRUCTURES & CARE ORGANISATIONS\* FOR BPSD

*The first dimension of Support Systems for BPSD in dementia*

\*SCO

### METHOD

- **Literature review:** A literature review was performed on original articles referenced in Pubmed from January 2000 to March 2012: 660 references were identified, 30 were relevant to the specific topic of SCO for BPSD.
- **Surveys:** A quantitative self-administered questionnaire was developed on National Programmes for Alzheimer disease, including 9 dedicated questions related to SCO for BPSD, with or without national dementia strategy. The questionnaire was sent via email to 28 European countries between March and September 2012. A qualitative and quantitative data analysis was performed, using both EpiInfo 3.5.4 and NVivo 10 software. Another qualitative self-administered questionnaire was developed to collect information about Support Systems, and, in particular, outstanding innovative SCO projects across Europe. The questionnaire was sent via email to ALCOVE Member States between July and Sept 2012. This non exhaustive survey aimed to better describe some specific SCO, running the spectrum from major research projects to minor care organisations, illustrating some innovative dynamics for managing BPSD. A qualitative analysis of the data was performed using a grid with shared criteria.

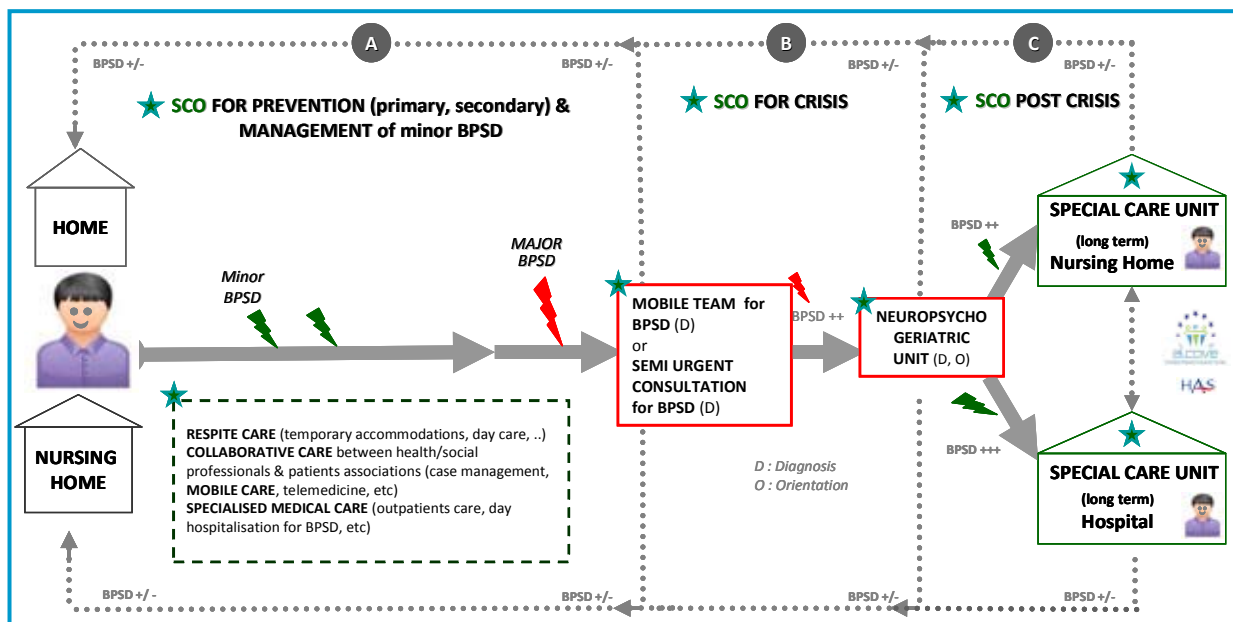
### RESULTS

- **Description of SCO for BPSD all along the patient pathway (Figure 1):** The SCOs were considered at all steps of the care pathway for the patient and the carer. These support systems bring some contributions to preventing BPSD and caring for persons experiencing BPSD. These SCO can be involved even before the first BPSD episode (primary prevention, step A), at the moment of occurrence of minor or major BPSD (crisis, step B), or after the BPSD episode (secondary prevention, step C).

The SCO which are principally involved at the prevention stage (step A) include “**respite care**”, such as temporary nursing home accommodations or day care, **collaborative care**, such as multidisciplinary interventions at home or in a nursing home, and special medical care involving the GP or specialised medical follow-ups performed in outpatient setting or in day care units, for example. Before considering hospitalisation in **specific neuropsychiatric units** for major BPSD or crises (step B), some structures propose innovative **outpatient consultation services or mobile teams dedicated** to BPSD. After the crisis (step C), patients presenting with persistent minor BPSD may be followed up with within **dedicated day care structures** and all SCO involved at the primary prevention stage, or may be admitted into **specialised units within nursing homes or hospitals** (Figure 1).

Figure 1. Structures and Care Organisations for BPSD all along the Patient Pathway

Step A: minor BPSD prevention & management - Step B: major BPSD crisis management - Step C: BPSD management & prevention



- Assessment of SCO for BPSD care in the literature people with dementia:** Very few studies evaluated SCO. When SCO were evaluated, it was done by using behavioural scales assessing and not exclusively the family carers. Nevertheless, collaborative care provided to the family carer and integrated within primary care involving multidisciplinary teams led by an advanced practice nurse may be more efficient in preventing BPSD than current care practices (1). Most of the studies which disclosed significant behavioural benefits have combined multiple approaches. Corbett et al. performed a systematic review of services providing information and/or advice to people with dementia and/or their carers (2). They found 13 randomised controlled trials in which 2 out of 3 measured quality of life and indicated benefits regarding neuropsychiatric symptoms. However, they did not address carer burden. Most interventions included key elements such as skills training, telephone support and direct help in navigating the medical and care system. There seems to be some support for the value of information services, however, more information is needed to determine the specific elements that are effective. Moreover, combined support for people with dementia and carers provided in Meeting Centres may be more efficient in improving behaviour and mood than regular day care support (3). In their 2009 review, Lai et al.'s (4) evidence for special care units pointed out that no randomised controlled trials meeting the selection criteria had been identified. France's new type of neuropsychiatric units dedicated to BPSD "Cognitive and Behavioural Units" has been recently evaluated in observational studies (5, 6). The NeuroPsychiatric Inventory score may thus decrease at the two week after discharge mark from a Cognitive and Behavioural Unit, in particular, the sub-scores assessing delusion, agitation, depression, anxiety, disinhibition and aberrant motor activity symptoms (6).
- Structures & Care Organisations for BPSD in Europe**
  - Quantitative analysis of the European Survey on SCO for BPSD.** Twenty-four questionnaires from 21 countries (there were more questionnaires than countries because of autonomous divisions within some countries) were collected for the quantitative survey (response rate: 87%). Survey results show that countries with a national Dementia strategy (national plan) have developed more SCO for BPSD than countries without strategies (see Table 5 p.33 Structures and Systems dedicated to BPSD).

These SCO are developed for the prevention and management of minor BPSD both in ambulatory settings (step A) and when individuals are at home, as well as for major BPSD (crisis, step B & post crisis, step C). The observed difference between countries with and without a national plan is statistically significant except for day hospitalisation (Figure 2a: SCO, step A) and hospitalisation units in neurology and in geriatrics dedicated to Alzheimer disease (Figure 2b: SCO, step B & C).

Figure 2a. Structures and Care Organisations for the Prevention & Management of minor BPSD (SCO step A)

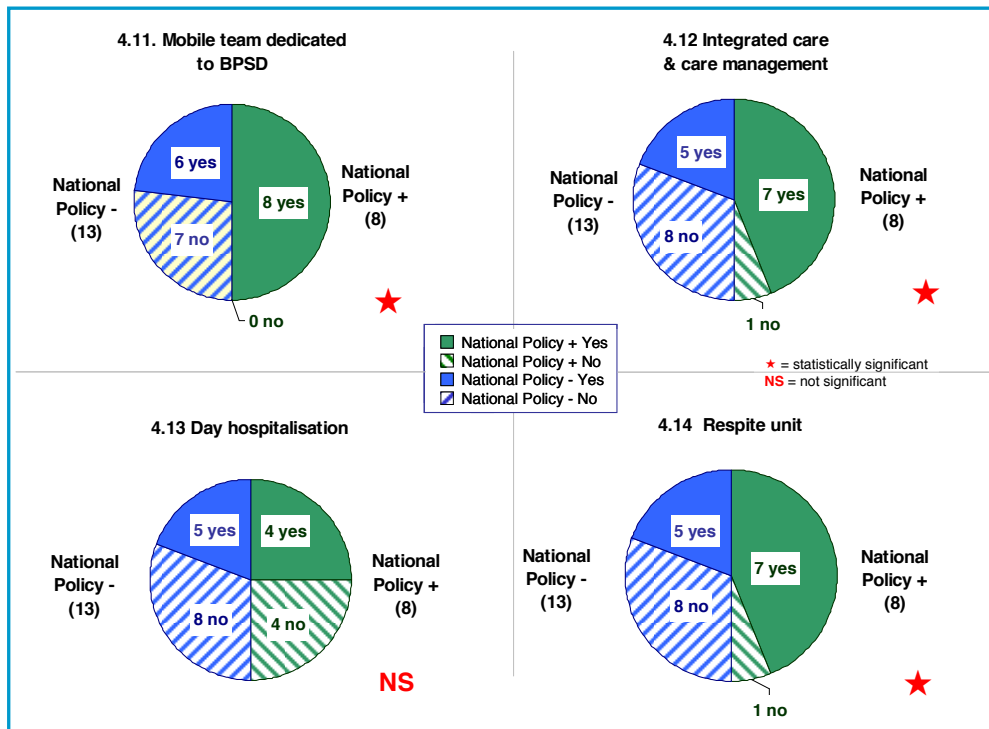
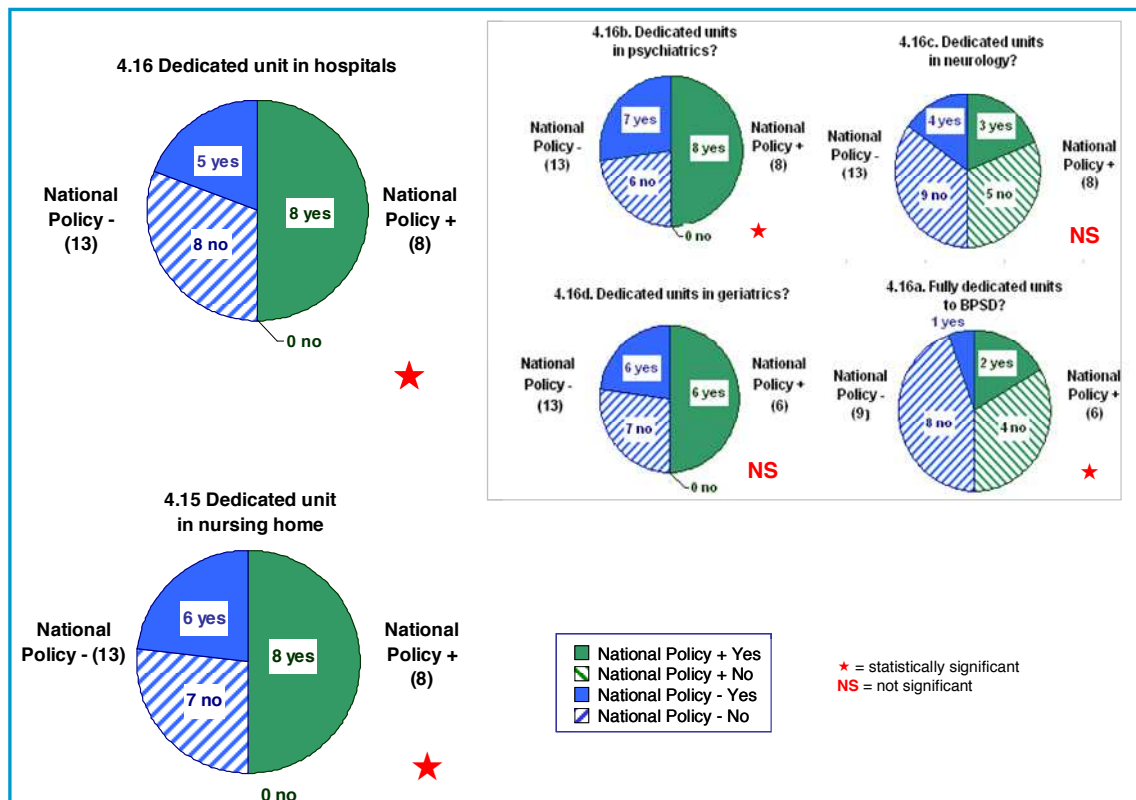


Figure 2b. Structures and Care Organisations for the Prevention & Management of major BPSD: Crisis (SCO step B) and Post-Crisis (SCO step C)



- **European Qualitative Survey on outstanding SCO projects for BPSD.** Fifteen responses from 5 countries were collected. Collected projects could be classified into 3 types: Home interventions/case management (e.g. Home support in France, see below); Hospital and Nursing Home dedicated units; Registries collecting data from various SCO about people experiencing BPSD (e.g. The national Swedish BPSD Registre, see below). All referenced projects or programmes are included in the ALCOVE Toolbox

#### Home support provided by multidisciplinary specialised teams to prevent BPSD in France

International scientific literature and clinical studies show that multidisciplinary home interventions involving specialised nurses and other carers such as psychomotor therapists and occupational therapists bring significant benefits to the prevention and care of behavioural disorders (8, 9). Therefore, the French Alzheimer Plan has set up specialised teams within the framework of home nursing services. These are spread out equitably across France. Based on the medical prescription, teams combining the intervention of gerontological assistants, occupational therapists and psychomotor therapists visit the home. As soon as a diagnosis of dementia is made, these teams educate the person living with dementia, and assess the need for housing adjustments, rehabilitation and cognitive stimulation and help with behavioural problems.

#### The National BPSD Registry in Sweden

This national quality registry initiated in November 2010, aims to improve and guarantee the quality of the treatment and care for persons experiencing BPSD (7). All included persons are assigned a score using the NeuroPsychiatric Inventory, and basic information such as diagnosis, age, gender, all medications used and different non pharmacological care interventions applied are registered. BPSD profiles are created and the different interventions applied are followed up with and evaluated continuously, with automatic feedback given to the teams for making quality improvements. To date, 216 municipalities and 1,505 units, nursing homes and BPSD-teams in specialised clinics are participating in the registry which monitors 5,350 patients. The registry is being expanded rapidly throughout the country. This information is used to gather knowledge on BPSD prevalence, BPSD prevention and management and quality improvement. Preliminary results will be available by the end of 2013. This national, person-centred support system is an example of sharing medical & social information concerning persons experiencing BPSD, whatever their SCO may be.

## RECOMMENDATIONS ON STRUCTURES & CARE ORGANISATION FOR BPSD

*The first dimension of Support Systems for BPSD*

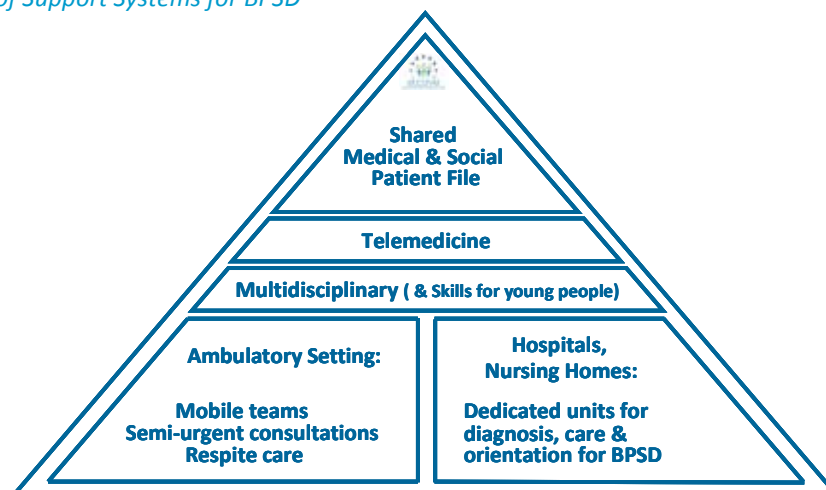


Figure 3. Structures and Care Organisations (SCO): Pyramid of Recommendations

The recommendations at the foot of the pyramids are fundamental, with subsequent levels covering more sophisticated objectives

Recommendations on Structures & Care Organisations for persons experiencing BPSD are the following (Figure 3):

- [1] Ambulatory SCO for persons experiencing BPSD should be developed**, because it is crucial to prevent and manage BPSD at an early stage. This will enhance the person's possibilities to live at home as long as possible.

Mobile teams with specific skills for the caring of BPSD, both in the home and nursing home setting. For instance, specific mobile teams dedicated to BPSD in high population density areas and specific competencies within geriatric mobile teams in low population density areas.

Semi-urgent consultation for BPSD (delay < 1 week): at the hospital or via telemedicine, the aim being to respond quite rapidly to behavioural disorders so as to prevent emergency hospitalisation. Different specialists, such as neurologists, geriatricians or psychiatrists could perform such a medical consultation. A multidisciplinary approach involving specialised nurses and psychologists as well as providing telephone support to the person and/or his or her carers may be also useful.

Respite care possibilities are necessary because it appears crucial to help informal carers by giving them a break from caring for the person when needed. This would serve to prevent psychological and physical carer exhaustion. Literature analysis shows that good carer health can prevent BPSD. Respite care possibilities include day care centres and temporary accommodations for the person living with dementia, and home professionals to support the carer.

- [2] Dedicated units for BPSD in Nursing homes and Hospitals should be developed** because the development of this kind of nursing or hospitalisation unit has already shown to be of dramatic help for patients presenting with major BPSD in several European countries.

- [3] A shared medical and social patient file as an optimal tool, key to an indispensable multidisciplinary approach, should be promoted**, because for high care efficiency it appears important to rapidly share medico-social, clinical, diagnosis, psychological and behavioural data regarding the patient and the main carer. A shared file would need to be kept up to date all during the patient care path.

A multidisciplinary approach should be adopted at each structural level (nursing home, dedicated unit for BPSD, mobile team) and at the patient-centred pathway level (general practitioner, other physicians, case manager, therapist, social workers etc.) A specialised nurse-led multidisciplinary team including psychomotor therapists and occupational therapists has been shown to be beneficial in the prevention and care of minor BPSD in people living with dementia at home. As concerns more severe BPSD, the intervention of a medical doctor and a psychologist would be useful in preventing emergency hospitalisation.

Consider specific skills key to young patients' care among all SCO, because of the specific needs of these people and their families.

- [4] Quality and impact indicators for persons experiencing BPSD, family carers and professional carers should be collected** because it is crucial in daily practice to assure and monitor the quality of care within the different SCO. To set up new SCO for research purposes and in order to guarantee the usefulness of SCO in the real world, it is necessary to follow impact indicators which also target professional carers (see ALCOVE Toolbox for criteria).

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### NON PHARMACOLOGICAL & PHARMACOLOGICAL THERAPIES FOR PEOPLE EXPERIENCING BPSD

#### METHOD

- **Literature review:** The objective of this chapter is to investigate BPSD management. A literature review covering two databases, Cochrane and PUBMED, was performed. First, we searched for available studies on BPSD management by using the following key words: BPSD, behaviour, dementia, management and therapies. Limitations were: RCT, five years, and text or abstract available, randomised control trial or review. Study protocols were excluded, 17/125 abstracts were extracted from the Cochrane database for further review, as well as 148 abstracts from PUBMED.

#### RESULTS

- **BPSD management at the individual patient level (pharmacological & non pharmacological):** The primary management strategies for a person experiencing BPSD, include:

- 1) always treating the underlying disease when possible, AND adopting non pharmacological approaches to relieve the symptoms causing distress by assessing the underlying needs of the person
- 2) treating concomitant diseases and symptoms when appropriate.

Furthermore, marking a division between pharmacological and non pharmacological treatments may not serve our purposes. Rather, person-centred approaches centred in the person's and carer's needs should be adopted. The non pharmacological and homeopathic therapies used to treat BPSD as listed in the literature are listed in Table 1, and BPSD pharmacological therapies are listed in Table 2.

The literature review unveiled the thinness of evidence in existing studies as to the efficacy of non pharmacological approaches in BPSD management. Most of the benefits shown were either achieved when pooling data from several studies and approaches, or from multicomponent studies which included the possibility of tailoring the interventions individually. Thorough cost benefit analyses of non pharmacological therapies, including those that individually tailored support to meet personal needs, are few but promising.

In addition, it is important to keep in mind that several effective pharmacological treatments may have serious adverse effects e.g. antipsychotic medications, mood stabilisers such as carbamazepine, or valproate. Because of their negative benefit/risk balance in BPSD treatment and because of their high rate of prescription, long term antipsychotic limitation is a crucial safety topic (see Chapter ALCOVE Toolbox p. 84).

Table 1. Non pharmacological and homeopathic therapies according to their impact on BPSD

Therapy	Evidence	Therapy	Evidence
Acupuncture for vascular dementia	I	Massage and touch	W/I
Antioxidants	I	Multisensory stimulation	I
Aroma Therapy	I/NE	Music therapy	I/W/C
Behavioral interventions:Agitation	S	Transcranial magnetic stimulation	I
Behavioral interventions:Depression in PWD	S	Transcutaneous electrical stimulation (TENS)	W/I
Behavioral interventions: Need driven in PWD	S	Physical activity	I
Bright light therapy#	NE/W	Reminiscence	W/I
Cognitive stimulation#	W/I	Robot	W
Cognitive training	I	Snoezelen	I
Dog assisted therapy	I (W)	Support and psychotherapy	S
Environment	W/I	Validation	I
Exercise	W/I	Yokukansan	W/I
Homeopathic methods	I	Non pharmacological studies in BPSD	S
Horticulture	I	S=strong evidence, W=some evidence, weak, C=controversial evidence, I=insufficient data, NE=No evidence# Multicomponent interventions (see Method for specifications)	



Table 2. Pharmacological therapies as to the disease index and some concomitant diseases according to their impact on BPSD

Therapy	Evidence	Therapy	Evidence
Antidepressants in Dementia#	NE	Melatonin	W/C
Antipsychotic (atypical)	S*	Memantine	S
Cannabinoids	NE/I	Modanafil	NE
Cholinesterase inhibitors for BPSD	S/I	Mood stabilizers#	W
Cyproterone	W/I	Oxytocin	W/I
Donepezil	W	Prazosin	W
Gingseng	I	THERAPY FOR CONCOMITANT DISEASES SYMPTOMS	
Hirudin + Donepezil	W	Malnutrition	I
Cerebrolysin + Donepezil	NE/W	Pain	W

CAUTION: Because of their negative benefit/risk balance in BPSD treatment & because of their high rate of prescription, long term antipsychotic limitation is a crucial safety issue

S=strong evidence, W=some evidence, weak, C=controversial evidence, I=insufficient data, NE=No evidence # heterogeneous group, results may vary

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## OVERVIEW OF INTERVENTIONS FOR FAMILY CARERS

A general review of educational and social supports for family carers was performed as well as a separate review focused on psychosocial interventions (PSI) and BPSD outcomes.

### METHOD

- **Literature review:** The literature review was performed for educational and social supports for informal carers. An Internet-based search of 10 previous EU projects and 3 dementia networks and their results concerning dementia and BPSD was conducted. 9 publications were extracted from Cochrane and 47 from PUBMED.

### RESULTS

- **Main findings:** The main findings were the following:
  - Multicomponent information services are beneficial, particularly if they include psychosocial interventions (PSI). Therefore the PSI were also evaluated separately (see next review): Focus on PSI & BPSD
  - Carer support, including information and education, showed:
    - strong evidence of reducing depression; may have impact on the informal carer's care burden
    - underutilised potential for reducing care costs
    - some evidence of reducing BPSD
  - Gerontechnology is promising and
    - shows evidence as a source of information and social support
    - has a conditional effect which depends on the type of technology, its purpose, the design and individual tailoring of the programme, the target person of the programme e.g. care recipient vs carer
    - however, available human contact may be needed to increase feasibility

- may be useful in solving some safety issues
- Respite care
  - Definitions for respite care varied depending on whether programmes for the person with dementia and BPSD were available or not
  - Day care programmes designed for respite care are effective. However, attention should be paid to the availability of any multicomponent, individually-tailored programme targeted to BPSD.
- A care coordinator was useful in organising collaboration among persons with BPSD and their carers and included a cost benefit. Such coordination may delay institutionalisation.
- Special care units were superior in managing depression and avoiding physical restraints than in ordinary nursing homes, however their use of antipsychotic drugs was higher.
- Assessing and meeting the needs of both the care recipient AND the informal carers is necessary

## FOCUS ON PSYCHOSOCIAL INTERVENTIONS & BPSD

One of the most demanding and difficult aspects of care for family carers is the management of BPSD. Non pharmacological interventions are recommended as the first step of BPSD prevention and management, but there is a lack of precise recommendations concerning family carer interventions. The objective of this work was to assess the effectiveness of informal carer interventions and, in particular, PsychoSocial Interventions (PSI) for BPSD prevention and management, as well as proposing a classification system for these interventions and assessing their implementation and further needs across Europe.

### METHOD

- **Literature review:** A systematic review was conducted through the use of different databases (PUBMED, COCHRANE, WOS, PsycINFO, Psycarticles, Alzforum) of all interventions involving informal carers, either alone or with the patient, and having an outcome related to BPSD. The search was limited to the past twelve years. Guidelines, reports, meta-analyses, systematic reviews, randomised controlled trials, and clinical trials were included. The quality assessment for each article was assessed based upon the SIGN criteria and each article was analysed with the same criteria grid. The selected outcomes included the ability of the carer to prevent and manage BPSD and/or a decrease in BPSD using the NeuroPsychiatric Inventory and/or a decrease in antipsychotics prescriptions and/or a delay in institutionalisation and/or a decrease in the use of emergency services.
- **Surveys:** A self-administered quantitative questionnaire was developed to collect information about outstanding care-giver interventions across Europe. The questionnaire was sent via email to 41 national or regional Alzheimer associations thanks to and via Alzheimer Europe, to 24 national level health authorities who were asked to redirect it to the appropriate memory clinics, and to the French memory centres. Recipients responded during the period of July -Sept 2012. A qualitative data analysis was then performed. Another qualitative self-administered questionnaire was developed on National Programmes for Alzheimer disease (see p. 32) and included a dedicated question related to explicit actions for structured training for family carers. The questionnaire was sent via email to 28 European countries between March and September 2012. A qualitative data analysis was performed, combining the use of both EpiInfo 3.5.4 and NVivo 10 software.

### RESULTS

- **Data collected:** Included in the literature review were the following: 1 guideline, 2 reports, 12 meta-analyses or systematic reviews, 45 randomised controlled or clinical trials. The qualitative survey included 15 questionnaires completed by 15 different countries (response rates: Alzheimer associations: 34 %, European memory clinics: 24 %, French memory centres: 33%; please note that response was not mandatory if there was no outstanding project to describe). The quantitative survey included 24 questionnaires completed by 21 countries (there were more questionnaires than countries because of autonomous divisions within some countries, response rate: 87%).

- **Classification\*\*:** There is a great heterogeneity of terms used in literature to describe Psychosocial Interventions (PSI).

Based on the most recent literature, ALCOVE proposes to establish a terminology consensus and in doing so proposes classifying PSI for Carers & Patients, tailored to their respective needs, into 9 categories (Figure 4). PSI Carers and Patients are part of the IPCI (Individualised Patient and family Carer Interventions), with non pharmacological and pharmacological therapies for Patient. The IPCI is one of the 3 main dimensions of support systems for BPSD (Figure 9 p. 70).

- **Effectiveness in the literature\*\*:** The quality of intervention studies has improved over the last few years. There is strong evidence (level 1) that PSI are effective in decreasing BPSD and carers' negative reactions to these symptoms. PSI have comparable effectiveness or are more effective than antipsychotics and are safer, having no side effects (level 1). All interventions are not equally effective on BPSD. Comments on Figure 4 and the following:

- Multi-component interventions (1), tailored to the needs of both the family care giver and the patient, delivered at the patient's home with regular follow-ups are the best option (level 1) but it is not possible to precisely determine which strategy or specific components is most effective on specific symptoms. Multicomponent interventions [e.g. psycho-educational programmes (2) and home visits (4)] demonstrated efficiency in decreasing BPSD, improving carer outcomes and delaying institutionalisation.
- Psycho-educational programmes (2), rather than educational programmes (3), are effective in decreasing BPSD and improving carer outcomes (level 1). Use of theoretical models increases effectiveness and promotes transposition of these programmes.
- Home-visits (4) are effective for crisis management, and may be part of a more comprehensive BPSD prevention programme.
- No significant effects on BPSD outcomes have been shown for programmes that are (6) technology-based, (7) promote self-care techniques, (8) peer-support, or (9) conference/meeting/counselling, but these interventions are interesting when they are

combined with other interventions. The type of BPSD and carer characteristics can influence the efficiency of the intervention.

- There is still a need for an evaluation of the cost effectiveness of the different interventions, both on their own and combined with pharmacological treatments.

Figure 4. ALCOVE Classification of Psychosocial Interventions for Carers & Patients, tailored to their respective needs

1. Multicomponent (e.g. Psycho-Educational + home visit)\*
2. Psycho-educational programmes\*
3. Skills training & Educational programmes focused on the disease, therapies, environment,... \*
4. Home-visit/Mobile team\*
5. Activity planning, environmental redesign, Socio-cultural programmes
6. Technology-support for family carers (web or telephone support)
7. Self-care techniques for family carers (Cognitive Behavioural Therapy, stress management, coping with change as a result of caregiving)
8. Peer-support group
9. Conference/Meeting

\* Interventions demonstrated as effective on BPSD in the literature

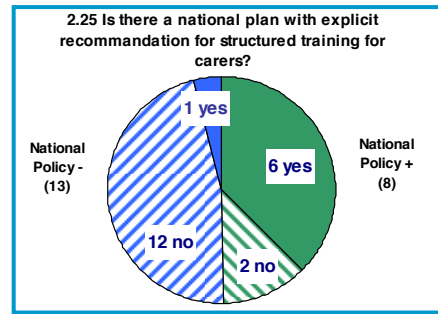
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- **Implementation across Europe**

➤ **The quantitative survey** found that only 7 European countries have made an explicit decision concerning structured training for family carers: 6 of these 7 countries are among the 8 countries with a national dementia policy in place, the 1 remaining country does not have a national policy, which is statistically significant. We do not have sufficient data to determine implementation of specific interventions at the European level (Figure 5).

Figure 5. Quantitative analysis of national strategies in Europe



➤ However, in the **qualitative survey**, the PSI programmes collected from 15 countries were consistent with literature findings. Multicomponent and psycho-educational interventions provide a comprehensive approach to BPSD (management skills, prevention, emotional management, treatment, structural factors). More than 2/3 of described PSI performed a self-assessment, with tools that are mostly evidence-based. Only the home-visit programmes provide a follow-up evaluation. All of these projects are available in the online ALCOVE Toolbox and in the WP6 ALCOVE report. Two examples are described below.

#### Psychological Interventions for Family Carers in Greece

A regional programme delivered at Memory clinics/hospitals/day centres in Thessaloniki, with a combination of multiple PSI:

- **Psycho-educational:** with active participation of the carers; provide information on an ongoing basis, and information for more effective care, coping strategies, shared experiences, psychological support
- **Support groups** aim to help the carers to be effective in their role and build up the necessary psychological skills to deal with difficult aspects of the disease and feelings of loneliness, loss and helplessness. Techniques from CBT
- **Family therapy** helps family members express their feelings, manage the challenge of care giving, deal with the changes in roles and develop communication skills, while supporting family adaptation.
- **Relaxation programmes** aim to reduce anxiety levels and manage psychosomatic symptoms using the therapeutic techniques of Progressive Muscle Relaxation and Autogenic Relaxation which lead to deep relaxation of the body and mind. Relaxation training sessions help carers to develop well-being and decrease stress levels
- **Web-based services** provide the opportunity to carers who cannot attend a traditional face-to-face support group due to geographic and time constraints to participate in an online support group. Group meetings are performed by online video conferencing through the use of a standard platform.

#### Community Service Programmes for people living with dementia in Cyprus

Mobile team interventions for persons living with dementia and their carers delivered at home by mental health service.

The psychiatrist first evaluates the patient who is usually accompanied by his or her carer. After this evaluation, the patient is referred to the community nurse trained in dementia and to the occupational therapist that has also been trained in dementia.

- The psychiatrist follows up regularly with the patient at the clinic and prescribes the needed medication. The psychiatrist has regular meetings with the other professionals who are also treating the patient. The therapeutic team evaluates and supports the family and the carers.
- The therapeutic team also provides programmes for persons living with dementia and supports the carers at Day Centres.

## RECOMMENDATIONS ON INDIVIDUALISED PATIENT & CARER INTERVENTIONS FOR BPSD

The second dimension of Support Systems for BPSD

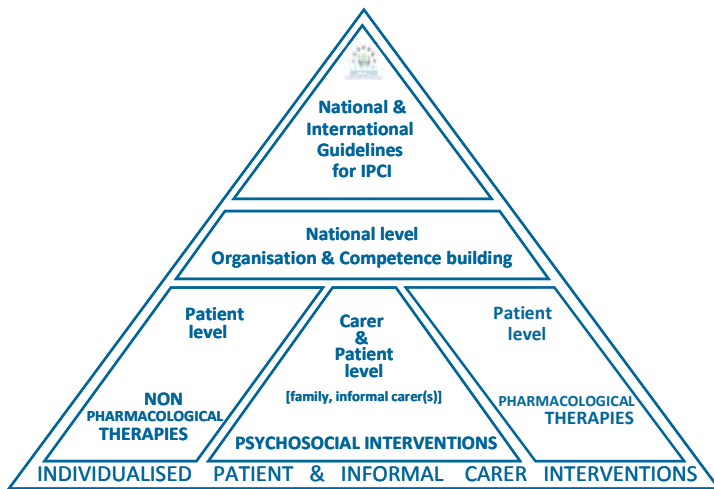


Figure 6a. ICPI Pyramid of recommendations for all Individualised Patient & Family Carers Interventions

The recommendations at the foot of the pyramids are fundamental, with subsequent levels covering more sophisticated objectives

Reminder: To clarify its recommendations ALCOVE proposes to distinguish among ICPI - Individualised Patient and family Carer Interventions - (1) the non pharmacological and (2) pharmacological therapies for the patient and (3) the psychosocial interventions for both carer and patient (also found in the literature as non pharmacological interventions).

Recommendations on Individualised Patient and Carer Interventions for BPSD are the following (Figures 6a & 6b):

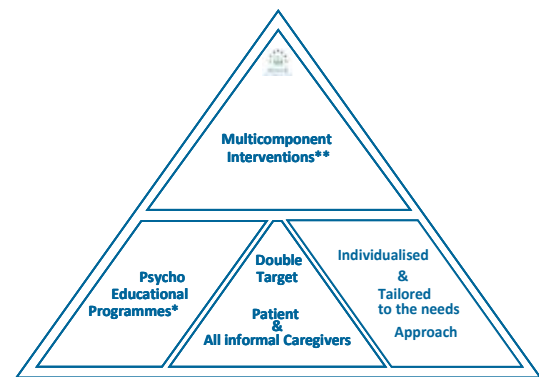
**[1] In terms of public health, the first line in BPSD prevention and management should be Psychosocial Interventions (PSI), and in particular, the first level should be psycho-educational programmes.** This is because PSI are effective on behavioural disorders (agitation, aggression, disruption, shadowing, depression, and repetitive behaviours other than psychosis) and safer than antipsychotics. More precise evaluations of PSI combined with non pharmacological therapies for the patient should first be performed to identify which combination strategy is most effective and should be evaluated in medical-economic terms.

Psycho-educational programmes must be part of national programmes also for dementia. This is because among PSI, Psycho-educational programmes (category 2, see PSI classification Figure 4) are effective in preventing BPSD and they are easy to implement. Increased effectiveness has been shown with the use of a theoretical model and with the active participation of the carer.

Multicomponent interventions could also be part of national programmes, because among PSI, multicomponent interventions (category 1, see PSI classification Figure 4 tailored to the needs of carer and patient, with periodic follow-up and home-delivered) are the most effective option. They are effective for patient and carer outcomes and delay institutionalisation. However, they require coordination between community and specialised settings and are much more difficult to implement

**[2] All Psychosocial Interventions should be double targeted, individualised & regularly revised** - PSI must implicate both the carer and the patient and they must be tailored to the needs of both the patient and the carer because the dynamics in their relationship can be a source of BPSD, and therefore, key to BPSD management. Their needs must be assessed with the use of medical and social expertise. This includes researching contributing factors for the patient and assessing carer burden, stress, quality of life and self confidence. Because both pharmacological and non pharmacological treatments may have adverse effects, because the status of both the care recipients and their carers may change, and because carers often need emotional support, the continuity of care and of support must be ensured.

**[3] A diagnosis approach & multiple therapies for BPSD should be applied at the patient level** - Evidence of managing BPSD in terms of individualised patient interventions should include 1) appropriate treatment of the disease index and in relevant cases: 2) research and treatment of the concomitant diseases and their symptoms (e.g. pain, balance, incontinence) combined with specific approaches for BPSD 3) non pharmacological and 4) pharmacological.



\* Multidisciplinary, in link with Patient & Family Associations, with information on BPSD  
\*\* Factors of efficacy on BPSD - Psychoeducational programmes, home site interventions, periodic follow up; coordination between community & specialized settings are required

Figure 6b. PSI Pyramid of recommendations For Psycho Social Interventions for Family Carers and Patients

## TRAINING & EDUCATION FOR PROFESSIONALS

### METHOD

- **Literature review:** A literature review for staff educational systems was performed. The literature was explored to find trials and systematic reviews that concerned the effectiveness of staff education for BPSD management. The databases used included Cochrane Reviews and the EBSCO Discovery Service, and these covered the following databases: Academic Search Elite, AgeLine, Business Source Index, CINAHL, ERIC, GreenFILE, Library, Information Science & Technology Abstracts, MEDLINE, PsycINFO, and SocINDEX with Full Text. Six systematic reviews and six controlled trials of appropriate quality were identified.
- **Survey:** A survey was sent to the ALCOVE partner countries concerning the educational frameworks in place ensuring the competence of care professionals in managing BPSD. The survey also sought to find how the competence of different care professionals encountering BPSD is ensured by basic and systematic post-basic education.

### RESULTS

- **Main findings in the literature:** Systematic staff training can be recommended to facilitate a unified, systematic way of handling persons experiencing BPSD in a care organisation.

It can also be stated, on the basis of general knowledge, although without specific evidence, that training usually does provide the trainees with improved resources to deal with BPSD. Policy recommendations need to be based in general knowledge of best practices (such as competence-based adult education principles) – not only direct evidence of training specifically addressing BPSD.

The learning process of how to deliver staff training seems to be ongoing with the creation of new evidence. Most staff members received their basic education on BPSD at least ten years prior, and many have received little or no education dealing specifically with BPSD management. Therefore, continuous or repeated education is necessary. It also needs to be kept in mind that “the absence of evidence is not evidence of absence”.

- **Situation in Europe:** Thirteen responses were received. This low response rate may reflect a basic difficulty in the approach, since the educational frameworks differ greatly from country to country, and the respondents may not have had enough information about all the different kinds of professional care education programs available in their countries.

It appears that these 13 ALCOVE Partners Member States, some kind of education, training or course focusing on memory diseases (including BPSD) is provided to care professionals. The programmes vary greatly in length, depth and the professions to which they are targeted, and especially in the emphasis that they place on BPSD. Also, the organisations responsible for the content of the education vary. The content may come from governmental organisations or patient organisations.

On-the-job training and staff education courses are seen by many, but not all, the respondents as an important component of competence development for BPSD management.

## CLINICAL GUIDELINES IN EUROPE

### METHOD

- **Survey:** Support for care professionals’ competence in dealing with persons experiencing with BPSD as provided by national clinical guidelines was evaluated by a questionnaire presented to the ALCOVE partners. A survey concerning the existence and contents of national dementia guidelines was sent to all Member States. The questionnaire provided information on 17 of the 19 participating countries, which represents 63% of the EU Member States.

## RESULTS

- **Situation in Europe:** In many countries, no national or widely accepted clinical guidelines exist that address care for BPSD. Most countries have guidelines on the management of Alzheimer's disease - all the guidelines stress the importance of using appropriate disease-specific medications, e.g. AChEI as the primary treatment - dementia or memory disorders, and these also cover BPSD. In France, the UK and the Netherlands, specific guidelines have been adopted for the management of BPSD.

All guidelines emphasise non pharmacological interventions for BPSD as primary. If non pharmacological treatment proves to be inadequate, pharmacological interventions could be applied. The guidelines vary as to the place of antipsychotics in the pharmacological approach and the information about their risk. Many guidelines emphasise the need to carefully evaluate and analyse any concomitant problems that may cause or exacerbate BPSD before deciding on any treatment.

## IMPROVEMENT PROGRAMMES FOR ANTIPSYCHOTICS LIMITATION IN EUROPE

The overprescribing of antipsychotics for behavioural disorders in dementia represents a major safety & ethical issue [1]. It is well known today that chronic exposure to antipsychotics is non-effective and deleterious for these people as it can lead to falls, excessive sedation, stroke and an increased risk of mortality, with an overall profoundly negative impact on the individual's health, ability to communicate and quality of life. The shared objective is to revise and modify prescription practices. Also, alongside general policies for dementia, including BPSD prevention and management (BPSD being the main cause of the prescribing of antipsychotics), ALCOVE aims to identify specific policy measures and/or national improvement programmes designed to inform about the risk of long term antipsychotic use in dementia and to limit their overuse in individuals living with dementia.

## METHOD

Three approaches were combined: a European quantitative survey, the consulting of websites, and directly contacting teams and experts throughout the ALCOVE network. This research strategy is not exhaustive and aims to share improvement programmes and tools. A self-administered questionnaire was developed on National Programmes for Alzheimer's disease, including 1 dedicated question related to an explicit general statement and/or recommendation for the « Reduction in the use of antipsychotic medication in people with dementia ». The questionnaire was sent via email to 28 European countries between March and September 2012. A quali-quantitative data analysis was performed, combining the use of EpiInfo 3.5.4 and NVivo 10 software.

## RESULTS

Among the 8 European countries having national Alzheimer plans, 5 responded that they have a dedicated general statement and/or recommendation regarding the reduction in the use of antipsychotics (see also ALCOVE survey on Clinical guidelines in Europe). ALCOVE has only received information about dedicated actions/programmes in national strategies for the limitation of antipsychotics in dementia with implementation and specific objectives from France and the UK. Of note, Italy has a specific legal framework for antipsychotic prescriptions and Sweden has developed a national BPSD registry. These programmes are described, along with all their tools, in the online ALCOVE Toolbox.

### The AMI Alzheimer programme in France [2] [4]

In conjunction with a national task force composed of health professionals and the other institutions, the French National Authority for Health has developed, within the framework of the French Alzheimer Plan, the programme: Alert and Mastering of iatrogeny (AMI) of antipsychotics in Alzheimer's disease. The objective of the programme AMI-Alzheimer is to reduce the inappropriate use of antipsychotics and to improve care for behavioural disturbances in dementia, while having recourse to other alternative treatments (for example: new care techniques) without deferring to other sedatives or physical restraints.

Dissemination of the AMI Alzheimer programme to all of the healthcare actors should provide for a common alert measurement at the national level (macro), regional level (meso) and even the local level. Only local alert/mastering actions led by teams and prescribers will allow for the reduction of the national alert. Furthermore, this national indicator has been implemented by various institutions.

The measurement of long-term antipsychotics and psychotropics prescriptions was performed using the 3 national insurance databases from 2007 to 2010. The French study showed that Alzheimer's patients and, in particular younger Alzheimer's patients, are overexposed to psychotropics and particularly to antipsychotics (AP). The rate of antipsychotics exposure in persons living with dementia decreased from 16.9% in 2007 to 15.5% in 2010.



### The Right Prescription in the United Kingdom [3]

The NHS Institute for Innovation and Improvement together with the Dementia Action Alliance, have launched a Call For Action to work together in a way that will unite them in their common cause to improve the quality of life of people with dementia and their carers by reducing the inappropriate use of antipsychotics for these people.

General practitioners, nurses, leaders in care homes, people with dementia and their families, pharmacists, psychiatrists and many others have organised themselves into eight groups who are committed to leading and taking action to ensure that every person with dementia on antipsychotic medication receives a clinical review and has an evidence-based, personalised care plan developed in partnership with them, their family and the multidisciplinary clinical team. The aim is that all people with dementia who are receiving antipsychotic drugs will have undergone a clinical review to ensure that their care is compliant with current best practices and guidelines, that alternatives to their prescription have been considered and a shared decision has been agreed to regarding their future care by 31<sup>st</sup> March 2012.

The National Dementia and Antipsychotic Prescribing Audit National Summary Report available online, shows over the last 5 years a decrease of 10.25 percentage points in the prescription of antipsychotic medication from 17.05 per cent in 2006 to 6.80 per cent in 2011. However, these results should be considered with caution due to the absence of information on potential deferral to other psychotropics' drugs; furthermore no data is available on the other 400,000 dementia people living with dementia in the UK, not included in this audit (ALCOVE Executive Board meeting 9-11 January 2013, [5]).

### A specific legal framework for antipsychotic prescription in Italy

In 2005, the Italian Medicine Agency (Agenzia Italiana del Farmaco), defined a programme of active pharmacovigilance for antipsychotics prescriptions and their role in the treatment of psychotic and behavioural disorders in persons living with dementia. The prescribing of antipsychotics for persons living with dementia should be made by authorised Specialist Centres as identified by their Region and in accordance with the Italian National Health System's reimbursement procedures.

In December 2006, it was decided that this prescribing of antipsychotics for persons living with dementia should be considered on a case-by-case basis, in accordance with each patient's clinical conditions and upon receiving informed consent from the person or his or her legal representative. A clinical pathway has been developed for the prescribing of antipsychotics in dementia for physicians operating within the Specialist Centres. Information on the impact of this policy in Italy has not yet been made available to ALCOVE.

### BPSD Registry & Quality improvement programmes in Sweden

This national quality registry initiated in November 2010, financed by the Swedish Association of Local Authorities and Regions (SALAR), is supported by a special Ministry of Health & Social Affairs programme directed at improving the situation for the most ill elderly. A web-based educational programme is mandatory before joining the registry.

The aim is to improve and to ensure the quality of treatment and care for persons experiencing BPSD. The settings are nursing homes, sheltered accommodations for persons living with dementia, and BPSD-teams at specialist clinics. To date, 216 municipalities, 1,505 units, nursing homes and BPSD-teams in specialised clinics and 5,350 patients are participating in the registry. The registry is being expanded rapidly throughout the rest of the country.

The development of BPSD profiles & different interventions are followed up with & evaluated continuously, with automatic feed back for quality improvement and follow up care. This registry is used as a foundation for quality improvement programmes.

## CONCLUSIONS

- **Key points for quality improvement:** Facing a risk situation, quality improvements must address 4 key points to ensure changes to current practice:
  - **Relevant references** must be made available (clinical guidelines, accurate information/knowledge, ...) and systematic reviews of prescriptions must be established (with the involvement of the prescribers, the pharmacists and all involved carers, ie. dedicated visits, multidisciplinary consultations, ...)
  - **Public campaigns** for health professionals, patients, families, carers, etc. These public education campaigns should be launched to raise awareness about antipsychotics risks and to inform about BPSD care, including non pharmacological alternatives to antipsychotics.
  - **Monitoring relevant indicators** (at the national/macrolevel, and at the local/micro level) is necessary, specifically in terms of impact and results. This would include collecting warning indicators on the exposure of individuals living with dementia

to antipsychotics, while taking into account the possible deferring to other sedatives or physical restraints (i.e. by audit, survey, registry, other databases).

- **A collaborative approach** must be applied with the Involvement of all stakeholders: health and social professionals, patients, carers, etc.

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## RECOMMENDATIONS ON WORKFORCE & SKILLS FOR BPSD

*The third dimension of support systems for BPSD in dementia*

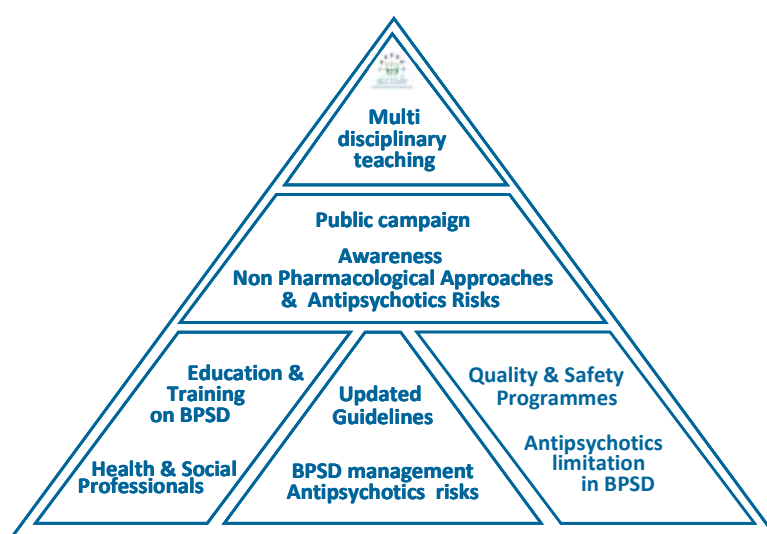
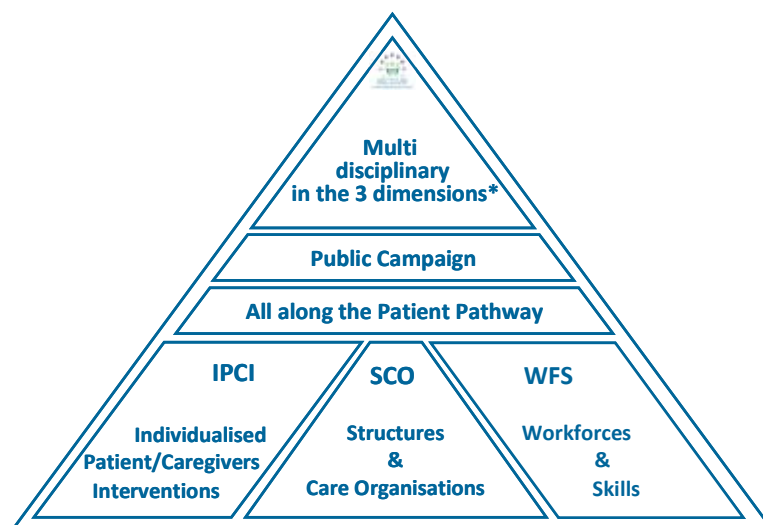


Figure7: Workforce and Skillsfor BPSD - ALCOVE Pyramid of recommendations

The recommendations at the foot of the pyramids are fundamental, with subsequent levels covering more sophisticated objectives

Recommendations on Workforce & Skills for BPSD are the following (Figure7):

- [1] **Access to education on BPSD has been shown to be necessary for carers, whether they are professionals or not.** Alarmingly, little information was available in the research literature on the impact of teaching BPSD at the basic level, e.g. in nursing schools or schools for other professionals. However, any teaching of care professionals seemed beneficial.
- [2] **Homogeneous guidelines on BPSD management and the side effects of antipsychotics should be disseminated.** Of the European ember States, 63% had national guidelines for dementia. However, only six guidelines addressed BPSD. However, it is important to keep in mind that not all BPSD affect the person living with dementia negatively and each person has different symptoms and needs. Therefore the guidelines should address the necessity of meeting both the care recipient's and the carer's needs with multicomponent and individually tailored programmes after having thoroughly and systematically assessed these needs.
- [3] **Quality and safety programmes focused on the limitation of antipsychotics are beneficial and complementary to the better management of BPSD in dementia.** The ALCOVE Toolbox provides tools and recommendations based on the ALCOVE European benchmarking. Quality improvements must address 4 key points: relevant references and systematic prescription reviews; public campaigns to raise awareness about antipsychotics risks and to inform about BPSD care; measurement and monitoring using relevant indicators at the national and local levels; collaborative approach with the involvement of all stakeholders.



\* IPCI: Multicomponents interventions; SCO: Shared medical & social patient file; WFS: Multidisciplinary teaching

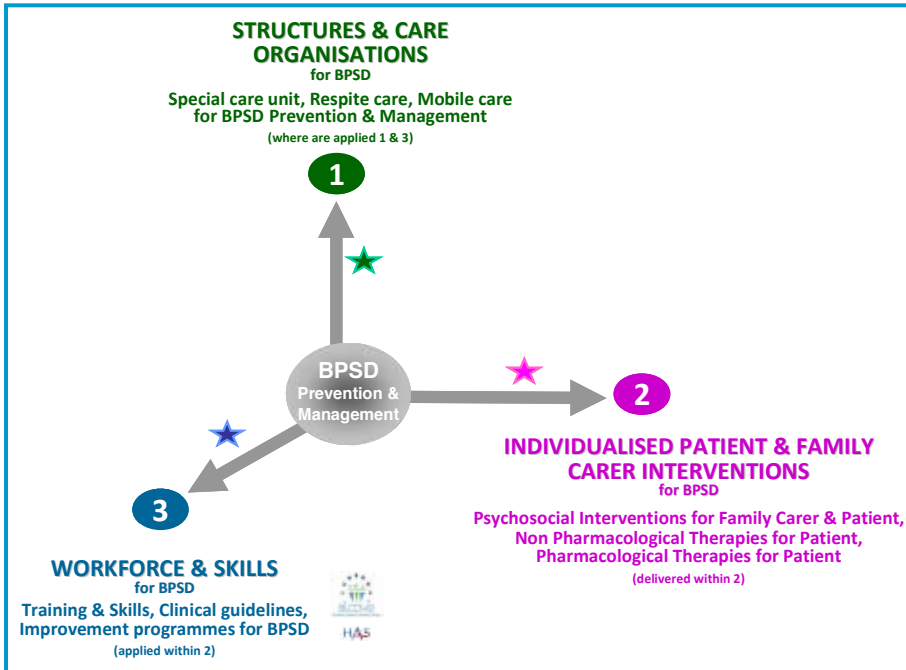
Figure 8. Global Strategy for BPSD: ALCOVE Pyramid of Recommendations

The recommendations at the foot of the pyramids are fundamental, with subsequent levels covering more sophisticated objectives

Recommendations for a global strategy for BPSD support systems are the following (Figure 8):

- [1] **Because BPSD are sources of family carer burden and depression, as well as an increased rate of institutionalisation of persons living with dementia, all nations should develop a 3-dimensional holistic strategy (Figure 9):**  
 1<sup>st</sup> dimension: how to develop structures and care organisations - SCO - for BPSD,  
 2<sup>nd</sup> dimension: how to implement individualised patient & family carers interventions - IPCI - combining psychosocial interventions for carer and patient and non pharmacological and pharmacological therapies for patient,  
 3<sup>rd</sup> dimension: how to ensure a skilled workforce - WFS - with systematic education programmes for health & social professionals.
- [2] **These 3 dimensions of BPSD Support Systems should be adapted and implemented at each step of the patient pathway (Figure 10):** for the prevention and management of minor BPSD (step A), for major BPSD crisis events (step B) and for the post crisis phase (step C) including secondary prevention. These implementations should be designed with close cooperation between decision makers, health and social services, and professionals and patient and family associations.
- [3] **Public information on BPSD prevention and management and about antipsychotics' risks should be part of general awareness campaigns for decreasing fear and stigma about dementia.**
- [4] **A multidisciplinary approach in all dimensions of Support Systems for BPSD should be promoted.**


Figure 9. ALCOVE “3D view” on Support Systems for BPSD 

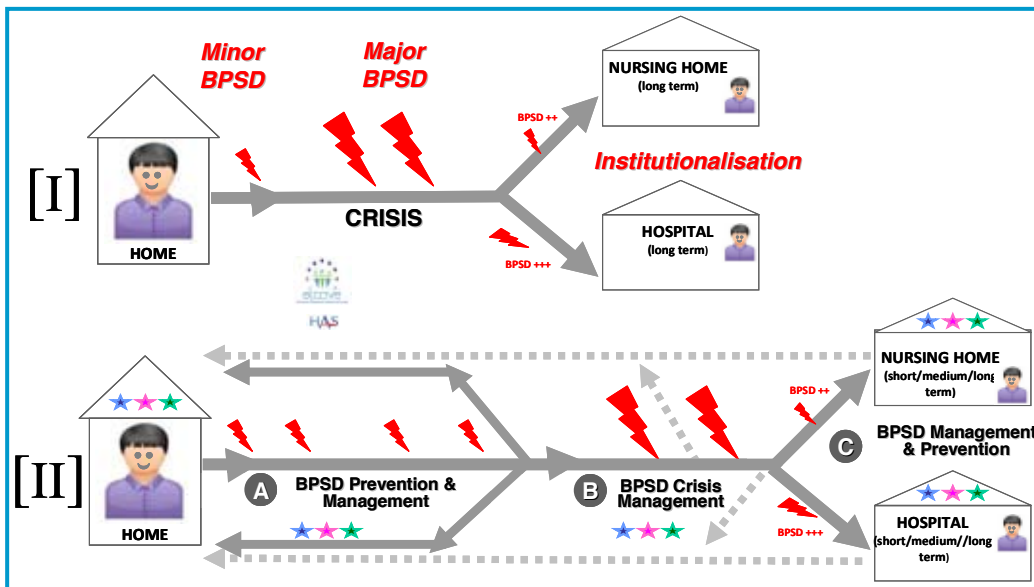


Comments Figure 9:

The 3 dimensions of BPSD support systems, i.e. structures and care organisations (1, SCO), Individualised patient and family carer interventions (2, IPCI) and workforce & skills (3, WFS), are independent and represent 3 “orthogonal” axes resumed as a “3D view”. All combinations involving some particular SCO, applying diverse IPCI (i.e. non pharmacological interventions) and some WFS (i.e. trainings and skills) may be thus considered.

The “3D view” is not fully taken into consideration in literature since numerous interventions combine the evaluation of SCO, such as day care centres, IPCI, such as psychosocial interventions, and WFS, such as specific professional education programmes. Furthermore, most of the studies mix functional, cognitive and behavioural evaluations, both in the patient and the carer. Disentangling these multiple interventions and approaches helps to better evaluate them, and more importantly, to consider the best combination.

Figure 10. Patient Pathway without [I] and with [II] dedicated 3D Supports Systems for BPSD  
The 3 dimensions of BPSD Support Systems  (see Figure 9) are applied all along the Patient Pathway



Comments Figure 10:

[I]: Without 3D support systems for BPSD

[II]: With 3D support systems, there are less BPSD crises and they occur in later phases of the disease. The quality of life of persons experiencing BPSD and their carers is preserved. Out- or in-hospital care and services taking care of persons experiencing BPSD vary. With these support systems for minor and major BPSD, persons could stay at home longer.

Step A: minor BPSD prevention and management

Step B: major BPSD crisis management

Step C: BPSD prevention & management