

Managing behavioural and psychological symptoms in people with dementia and their carers living at home/community- A mixed methods evidence synthesis for non-pharmacological interventions

A summary report February 2015

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Plain English Summary

Background

Two-thirds of people with dementia live at home and many experience distressing symptoms such as aggression, wandering, agitation, emotional problems, known as behavioural and psychological symptoms of dementia (BPSD), which result in poor outcomes. We aimed to combine evidence from various sources to find out what types of non-drug based interventions might be helpful for people with dementia and their carers. We also conducted focus groups (FG) and interviews with service users and providers around managing BPSD.

Findings

We found over 60 relevant studies of interventions aimed at people with dementia and their carers, over 50 relevant studies of views/experiences (qualitative literature), of which 24 studies informed the main findings. Our analysis included findings from 13 interviews with people with dementia, 12 interviews with carers, one FG of 7 carers and 24 service providers in 5 FGs.

Intervention studies identified different types of interventions (e.g. behavioural, memory stimulation, multi-component, art therapy, exercise, occupational therapy OT), relaxation, support, care provision or the education and training of carers.

Targeted behavioural programmes for carers which included carer education and skills training, BPSD management plans to help with coping and high level of carer involvement improved carer outcomes.

Evidence from low quality studies shows that some interventions may relieve symptoms in people with dementia (e.g. sensory enhancement, reminiscence for withdrawal) but continuous exposure may be required. Mentally stimulating activities can reduce apathy and depression in early stages, multisensory stimulation may improve well-being. Cognitive behavioural therapy targeted at people with dementia and carers may reduce depression and anxiety but larger studies are required. Multicomponent programmes of rehabilitation, trained professionals and care planning and delivery using behavioural protocols can improve BPSD symptoms and carer outcomes. Very few studies reported costs of delivering the interventions such that value-for-money could be assessed.

Common themes in the literature and interviews/FGs included challenges in recognising BPSD, difficulties in responding to types of BPSD (aggression, passive behaviours, repetitiveness, agitation), the impact of BPSD, interventions/support and barriers to services. Black and minority ethnic (BME) groups presented mostly with apathy, which was not adequately addressed by practitioners.

Intervention studies reported mostly depression, anxiety, distress and other BPSD. They focused on people who present with BPSD and qualitative data describe people who experience a continual building of BPSD until crisis (tipping point), supporting the service providers' reports that carers may delay seeking help. GPs sometimes fail to perceive the extent of the difficulties people with dementia experience and support may not be initiated early enough. BPSD affects people with dementia and carers in different ways, such as stress, social isolation, sleeping problems, strained relationship with partner, carer burden and coping difficulties. Intervention studies most commonly reported carer depression, burden, distress, bother with BPSD.

Qualitative literature and interviews/FGs suggest that helpful strategies for people with dementia and carers include a timely and appropriate diagnosis of BPSD in primary care, improved awareness of BPSD, having information and clear signposting to services in GP practices, specialist support including flexible respite care and improving carer skills in coping and managing BPSD.

BME groups (carer reports) may benefit from culturally sensitive outreach services, but evidence is limited. An accessible health and social care professional (e.g. key worker) to provide practical information with continual support could reduce carer burden. Literature suggests that the involvement of carers is important and service providers highlight the need for well-designed and coordinated plans. Both carers and practitioners may benefit from skills training and enhancement. Triangle of Care guidance needs to be used to ensure involvement of carers and professionals to meet their needs around BPSD management.

Conclusions

A unique feature of our study is that our focus was on older people with dementia living in their own homes and not care homes. The next steps to patient benefit should involve carers in the development and evaluation of interventions that help improve recognition of BPSD in primary care and post diagnostic support, including targeting BME groups who are under reported in literature. Identifying what is important at which point of dementia trajectory would be part of better evidence of 'what works'.

Keywords

Dementia, community dwelling, care giver, behavioural and psychological symptoms, systematic review, interventions, qualitative, experiences

Summary of Research and Findings

1. Background

Two-thirds of people with dementia (PWD) live at home and many experience non-cognitive behavioural and psychological symptoms of dementia (BPSD) at some point which often results in increased carer burden, high service use and unwanted moves to care homes. Previous research has focused on people living in long-term or mixed settings, and this project aimed to synthesise systematically the evidence on the effectiveness and cost-effectiveness of non-pharmacological interventions exclusively for PWD and carers living at home.

We conducted an evidence synthesis in the context of the recognition that older people and their carers living at home who rely on primary care may have specific needs requiring a range of support and interventions for managing BPSD. Many studies of the complex area of BPSD focus on one type of intervention or symptom, or on a narrow range of either. Synthesising evidence of a broad range of interventions for a diverse collection of behaviours provides an up-to date evidence synthesis of primary studies that focus specifically on people living at home that is complemented by data from PWD, carers and service providers providing a commentary on the relevance and validity of the review evidence for users and practitioners.

2. Research objectives

The key objectives were 1) to systematically review both quantitative and qualitative evidence about the management of BPSD in community-dwelling older PWD and their carers; 2) to evaluate the

evidence from the perspective of PWD, carers and service providers (SP); 3) to assess the resource implications of BPSD management interventions; 4) to test the findings with key stakeholders and 5) to develop recommendations for research, SPs and commissioners.

3. Methods

The review process is detailed in published protocol: Trivedi D, Goodman C, Dickinson A, Gage H, McLaughlin J, Manthorpe J, Ashaye K, Iliffe S. Syst Rev. 2013 Aug 28;2:70. doi: 10.1186/2046-4053-2-70).

Four components were specified in the two stage co-design:

- a) A preliminary stakeholder meeting to set review parameters of the mapping of literature on BPSD
- b) Stage 1: A systematic mapping of the broad literature on BPSD.
- c) Stage 2: An in-depth systematic review from the findings of the systematic mapping on appraising the evidence of effectiveness of particular interventions, and outcomes, including resource implications and evidence synthesis from qualitative literature
- d) Focus groups (FG) /interviews with carers, persons with dementia, service providers after the initial mapping phase (stage 1) and at the end to discuss the review findings with stakeholders, develop key recommendations for practice and research.

From stage 1 to stage 2: Priority for in-depth systematic review

As per our protocol, stage 1 to stage 2 was an iterative process of prioritising studies for inclusion in the in-depth review. We identified a substantial amount of literature for consideration in the in-depth review. This included quantitative (Randomised controlled trials (RCTs), non randomised controlled studies) and qualitative literature. We categorised the literature according to the extent to which the intervention included BPSD management as one component of the overall intervention and measured relevant outcomes. Due to the huge amount of literature retrieved, we have summarised findings from RCTs, (hierarchy of evidence), relevant qualitative literature and evidence from interviews and focus groups with people with dementia, carers and service providers. We have included data from interviews with black and minority ethnic populations, not identified in the literature.

BPSD literature is complex. Both the stage 1 mapping of evidence and stage 2 prioritising for an in-depth systematic review (SR) to address our stated aims and objectives included a large amount of literature. This present report for the NIHR RfPB includes evidence from RCTs, qualitative literature and interviews and focus groups.

3.1 Stakeholder meeting

We held a preliminary stakeholder meeting with health and social care professionals, SP and user representatives. The purpose was to identify key areas of interest and concern around the management of BPSD, search terms and to inform the review process.

3.2 Literature:

Search strategy: We conducted comprehensive and sensitive searches from various electronic databases, and lateral searches, and screened several reviews to identify studies conducted at

home/community. Studies were identified by computerised searches of PubMed, Embase, CINAHL, PsycInfo, AMED, HMIC, BNI, HEALTH BUSINESS ELITE, Scopus and Web of Knowledge (Web of Science). In addition we searched the Cochrane Library (including Cochrane Central Register of Controlled Trials (CENTRAL), Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects, Health Technology Assessment, Economic, Systematic reviews, Trials, Method, Techno). We carried out lateral searches (checking reference lists and citation searches) and screened several reviews to identify studies that included people with dementia living at home. An example search query from PubMed is presented in Box 1. Searches were conducted in October/November 2012 and then updated in May 2014 with a further PubMed search in March 2015. The broad mapping informed the selection of studies for our in-depth systematic review, through applying additional criteria and assessing the focus of complex interventions and BPSD relevant outcomes. Search terms are shown in Box 1.

Selection criteria: Non-pharmacological interventions delivered to older people with dementia and their carers who live at home/community. For the mapping phase stage 1, all study types were identified; for stage 2 in-depth systematic review additional criteria were applied for a manageable workload: RCT evidence and qualitative literature that examined views and experiences around BPSD management were prioritised.

Additional criteria to include for the in-depth systematic review:

- Post year 2000 to produce a review that is relevant to current practice
- Outcome evaluations that employ a comparison or a control group and report before and after changes in outcomes; (This would include RCTs and non-randomised studies)
- Qualitative studies of views and experiences of people with dementia/carers relating to interventions or support programmes (stated in objectives)

Outcomes

PWD: BPSD related (e.g. depression, agitation,), quality of life, level of independence, utilisation and costs of health and social services (including moves to long term care), and informal care (where available)

Carers: Carer burden/strain, distress, Quality of life related to BPSD management, carer psychological health

Process: provision of care, acceptability, feasibility

Views and experiences of service users

Screening for inclusion: All records were retrieved in Endnote and 10% were independently screened for potential inclusion. Hard copies of potentially relevant papers were further screened, with 20% screened independently and all checked by a third reviewer (due to a large volume of literature).

3.3 Data extraction and quality assessment

Descriptive and outcome data from included RCTs were extracted in Excel, using a pre-piloted form. Qualitative papers were imported into NVivo version 10 and analysed for themes. Quality assessment for RCTs and qualitative literature, and development of themes was conducted independently by two reviewers. A proportion of data extraction was conducted independently by two reviewers and checked by a third reviewer.

3.4 Stakeholder interviews and focus groups

We conducted interviews with PWD (13), carers (12), one focus group of 7 carers and 24 SPs in 5 focus groups.

4. Analysis and synthesis

Thematic analysis was employed for qualitative data to identify overarching themes related to BPSD. We used analytical software NVIVO 10 to analyse interviews, focus groups as well as individual studies that met the inclusion criteria. All qualitative data were examined in a number of stages, following a thematic analysis procedure¹. First the data were independently coded by two researchers and further examined for consistency by an independent reviewer. This led to an initial list of 12 themes and related codes applicable across all data. Using Tree Map and Cluster Analysis within NVIVO helped to further refine the themes. Following a discussion with the research team and project advisory group, a final set of five overarching themes were developed that captured the core processes of managing BPSD.

We classified the interventions according to target group, and broader groups of interventions based on the types reported by a previous review² to manage the heterogeneity of types of interventions. Study details and effect sizes on outcomes are presented in detailed evidence tables by study.

For resource use and cost data, due to numerous variables we have extracted selected key data and the effect sizes, as given by the authors. Moreover, the reporting was not comparable across the papers and key data are discussed within the context of interventions and outcomes to draw some conclusions on economic implications.

5. Results

Screening for relevance: We retrieved a total of 20,152 records. After de-duplication, we screened titles and abstracts of 16,341 records, of which 794 full papers were screened for relevance.

300 papers representing 229 studies were screened as meeting our broad inclusion criteria for the mapping phase. Studies were categorised according to research questions, study type, methods, participants, interventions and outcomes (relevant studies identified from updated searches were added to in-depth review inclusions). (See supplementary tables and list of all included studies).

Number and categories of studies we identified in terms of study types and relevance are shown at the end of the PRISMA flow chart (Figure 1).

Stage 1: Number of papers according to study designs which required key data extraction to enable us to reach stage 2 is as follows:

Outcome evaluations (OE): n=147 studies (n=178 papers), including RCTs (85 studies, 141 papers); non-randomised controlled before/after designs (36 studies, 39 papers); pre-post one group designs (26 studies; 26 papers); qualitative/views studies (23 studies, 30 papers including those related to

¹ Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., . . . Iliffe, S. (2012). Psychosocial Factors That Shape Patient and Carer Experiences of Dementia Diagnosis and Treatment: A Systematic Review of Qualitative Studies. *PLoS Med*, 9(10).

² Dickson K, Lafortune L, et al *Non-drug treatments for symptoms in dementia: an overview of systematic reviews of non-pharmacological interventions in the management of neuropsychiatric symptoms and challenging behaviours in patients with dementia*. 2012. <http://www.piru.ac.uk/assets/files/2012-1%20PIRU%20Publication.pdf>.

OE. Remaining papers were case studies, acceptability/feasibility, and protocols, methodological, cross sectional, cohort studies, case series, mixed methods. Non-pharmacological interventions identified were considerably heterogeneous and targeted people with dementia and carers, with over 50 types of interventions and significant variation in how outcomes are defined and measured. Identifying relevant studies for inclusion from stage 1 to stage 2 was iterative. Further screening identified a large body of relevant quantitative and qualitative studies, which meant that the focus of the review was on RCTs. (Updated searches identified additional 18 RCTs (aimed at BPSD) and 28 qualitative papers).

Key findings from included studies

In this section, we summarise results from *stage 2 in-depth systematic review* (synthesis 1), qualitative literature (synthesis 2) and qualitative data from interviews/focus groups with people with dementia, carers and health professionals/service providers.

Summary from RCTs, qualitative literature and interviews/FGs. (See supplementary tables of evidence)

5.1 RCT Evidence: (Evidence tables 1-3)

Papers which met our inclusion criteria were published from January 2000- November 2014. We screened titles and abstracts of 16,341 records, of which 794 full papers were screened for relevance. 300 papers representing 229 studies were screened as meeting our inclusion criteria for a broad mapping (Figure 1, Appendix 1). Identifying relevant studies for inclusion from stage 1 to stage 2 was iterative. Further screening identified a large body of relevant quantitative and qualitative studies, which meant that the focus of the review was on RCTs.

Seven studies targeted PWD only, 25 studies targeted dyads (PWD and their carers) and 37 studies targeted carers only. The interventions used were often multi-faceted, multidisciplinary, and varied in content, length, type and duration. They were delivered in homes, community or out-patient settings. BPSD management was part of a more complex intervention including other components (e.g. multi-component, behavioural, support, training and education). We classified the interventions according to target group, and broader intervention groups to manage the heterogeneity (behavioural cognitive stimulation, education and training, emotional, environmental, multi-component, organisational (e.g. care planning and delivery), physical and structured (e.g. art therapy, exercise, occupational therapy OT), sensory enhancement, support, technology).

Outcome measures used various instruments and various terminologies were described. Studies were based in the USA (n=37), Europe (n=13, UK n=7) and other countries. Most included mild-moderate stages of dementia. The quality of the studies was mixed, with 23 low risk (good quality), 34 unclear/high risk, 12 were low/unclear risk (moderate quality) (Figure 2, Appendix 1) and some categories of interventions had very few studies.

5.2 Qualitative data from literature and interviews/focus groups – (Evidence tables 4 – 7)

We identified 55 studies (57 papers), targeting a total of 1593 participants, 1322 carers, 182 PWD and 89 health professionals/ SPs. They were conducted in the UK (n=23), Europe (n=8), and USA (n=6) and other settings. Most PWD lived with a spouse/partner and had mild-moderate dementia

(tables 4 & 5). An in-depth thematic analysis was conducted on 24 contextually rich papers, with an overview on the rest (tables 6A-6C). Key characteristics of interview/FG data are shown in tables 7A – 7D.

5.3 RCT evidence summary per target group

Dyads and carers

Behavioural interventions: Behavioural management is overall not significantly effective on BPSD outcomes at short or long-term follow-up. CBT may be effective in improving anxiety and cost neutral (Spector et al 2014), although high level of carer involvement might be required. Preliminary results from small pilot studies suggest that CBT has the potential to improve carer outcomes, but larger studies are required.

Education and training: Good quality education and training interventions improved one or more carer outcomes related to problem behaviours including depression and carer distress, positive affect with BPSD appraised by carers as less stressful and bothersome, response to disruptive behaviours, with decrease in frequency of behaviours, improved care recipient's Quality of life, carer burden and coping.

RCTs: Multifaceted and effective interventions for carers included: carer education and skills training (psychoeducational, psychosocial, skills enhancement, BPSD management plans), coping strategies, high level of care involvement in interventions, with carer support. Remains a gap in practice as carers report not being aware of education and training programmes that could be beneficial.

Training health professionals (e.g. occupational therapist, nurse) can have a vital role in improving outcomes. Qualitative data supports RCT evidence.

People with dementia: Very few low quality studies suggest that some interventions may relieve symptoms (e.g. sensory enhancement, reminiscence for withdrawal). Mentally stimulating activities can reduce apathy and depression in early stages. Multisensory stimulation and enhancing function may improve well-being, but high quality studies are needed to establish effectiveness. Cognitive behavioural therapy may reduce depression and anxiety but larger studies are required.

Multicomponent programmes of rehabilitation, trained professionals and care planning and delivery using behavioural protocols can improve BPSD symptoms and carer outcomes. Physical and structured interventions that include OT can also improve engagement and have the potential for benefit.

Cost effectiveness: A wide range of interventions have been trialled in different countries and settings. Some address BPSD directly, and others target broader issues (e.g. carer coping). Although most papers described (to some extent) the resources involved in delivering the interventions (staffing, number of sessions, facilities and materials), these were rarely converted to a cost so that any estimate of value-for-money could be derived. Future studies should include a full cost effectiveness analysis, although where impact on BPSD is incidental (e.g. carer depression) rather than the primary outcome, and when interventions are multicomponent, problems attributing input to effects may arise. Very few studies reported costs of delivering the interventions such that value-for-money could be assessed.

5.4 Themes from qualitative literature (supplementary tables 6A-6C) and interviews/FGs (supplementary tables 7E -7H)

Common themes from qualitative literature and interviews/FGs data included: challenges around recognition and diagnosis of BPSD, difficulties in responding to types of BPSD, impact of BPSD on carers, interventions/support for PWD and for their carers and barriers to support for BPSD management. Overlaps and divergence between the sources of data are shown in section 6, project report, Appendix 1.

-RCT and qualitative research addresses mostly people with mild-moderate stage of dementia for community dwelling people

-Challenges around the recognition/diagnosis of BPSD in PWD in primary care resulting in delays in early intervention. GPs are usually the first point of contact, but they sometimes were thought to fail to perceive the extent of the difficulties people with dementia experience (see also barriers). RCTs focus on people who present with BPSD and qualitative data describe people who experience a continual building of BPSD until crisis (tipping point), supporting the SPs' reports that carers may delay seeking help. BME interviews report that some behaviours may be stigmatised and mistaken for old age, but practitioners may not have experience of dealing with BME issues.

- Difficulties in responding to types of BPSD: Qualitative literature and interviews/FGs most commonly mentioned aggression, passive behaviours, risky strange embarrassing behaviour, repetitiveness, agitation, confusion. These types of BPSD have a direct knock-on effect on carers, building up the level of stress and desperation, which then becomes a vicious circle for some, leading to a "tipping point" when they cannot cope anymore. RCTs described, depression, anxiety, scores from neuropsychiatric and revised memory and behavioural problems checklists, few reported agitation, apathy, distress, aggression; health professionals described depression, withdrawal and apathy as major types, although some were easier to recognise than others; carers reported aggression and passive behaviours. BME groups presented with apathy and aggression, too complex to deal with, and not adequately addressed by health professionals.

-No shared language around definition and understanding of BPSD, particularly the qualitative evidence found that the categories were not always recognised or used by professionals nor recognised or seen as capturing their experience of BPSD by formal and informal carers

-Impact of BPSD on carers and people with dementia: Qualitative and quantitative data match in terms of BPSD impact on carers, who mostly deal with managing disruptive/problem behaviours, aggression. BPSD are difficult to handle and have devastating impact on carers by causing, for example, strains to the relationship, burden to the family or distress. Additional reported symptoms were social isolation, sleeping problems, carer burden and coping difficulties. Intervention studies most commonly reported carer depression, burden, distress bother with BPSD, coping problems.

-Qualitative literature and interviews/FGs suggest that helpful strategies for PWD and carers include a timely and appropriate diagnosis of BPSD in primary care, improved awareness of BPSD, having information and clear signposting to services in GP practices and specialist support including flexible respite care, and enhancing carer skills in coping and managing BPSD.

-Carers and PWD from qualitative data report benefit from music, reminiscence, counselling, technology (GPS) and identified need for appropriate/targeted support programmes. Carers from interviews/FGs reported the value of admiral and district nurses. BME groups (carer reports) may benefit from culturally sensitive outreach services, but evidence is limited.

Barriers and facilitators from qualitative data: availability of appropriate interventions, lack of awareness in primary care, information on follow-up services ; health professionals report that some carers are unable/ unwilling to implement strategies, denial, lack of adequate training for professionals, carers unaware of education and training programmes. BME groups in the UK are stigmatised, voices not heard, lack understanding of BPSD in dementia trajectory, cultural needs, benefit from outreach services, neglected in the research literature.

The qualitative data suggested some potential facilitators that seem to remit some of these problems, such as enhancing levels of integration between specialised services and primary care or carer awareness training. Additional facilitators include patient support groups, better communication with local services and improvement of training for GPs and other primary health care providers to recognise BPSD and initiate appropriate interventions.

6. Implications for practice and research

-Evidence supports the development of multi-faceted interventions that include carer education and training components, skills enhancement and training for coping strategies, behavioural protocols
-Training of health professionals is important as they may have a vital role in delivering interventions to improve outcomes. This provision to target BPSD management needs to be examined in practice.

-Interventions that improve carer-PWD interactions are important, and should be tailored to match the PWD/carers' characteristics and preferences.

- Evidence supports the use of Triangle of Care type initiatives that require the carer, professional and person with dementia to be involved in the implementation of multi-component interventions to resolve, reduce and manage the impact of BPSD.

-Collaborative care, planning and delivery which include specific behavioural intervention protocols with input from primary care professionals can be effective. SPs highlight the need for well-designed and coordinated plans

-Improve recognition that BPSD is present and worsens and there is a need to incorporate earlier assessment and interventions that support prevention

-GPs and practices to provide clear signposting for services for dementia carer and PWD. Local provision to carers needs to be monitored

-An accessible health care/social service professional able to provide practical information and help could contribute to the relief of carer burden (e.g. admiral nurse, culturally sensitive outreach services for BME groups, key worker for continued support)

-Professionals may believe that dementia care pathways are in place but patients and carers seem not to know or have different experiences.

- Stakeholders report that flexible and rapid respite are needed so as to respond to BPSD which can change quickly (lack of RCT evidence)
- Engagement of PWD in meaningful activities can be beneficial (e.g. sensory enhancement, mentally stimulating activities, reminiscence), but the evidence is weak and high quality studies are required
- High quality research examining components of multifaceted interventions for dyads that contribute to effectiveness on both people with dementia and carer outcomes with full economic appraisals
- Interventions targeted to BME populations need to be developed and to identify what is important at which point of dementia trajectory
- Qualitative research on BPSD management in BME groups informing a culturally tailored intervention and its evaluation is required

7. Expected impact

Our wide and comprehensive review has provided us with an up to date evidence of more relevant material specifically for community dwelling people (not in care homes) on what is already known about types of interventions and their effects as well as service user experiences. In addition, we have examined data from interviews/focus groups with PWD, carers, SPs and commissioners. It provides a benchmark and evidence base for dementia specific commissioning and, the development of interventions considering the barriers highlighted. It also highlights research priorities for BPSD management and patient benefit.

8. Conclusions

A unique feature of our study is that our focus was on older PWD living in their own homes. We identified a large body of literature on interventions and views of carers of PWD with BPSD. The next steps to patient benefit should involve carers in the development and evaluation of interventions that help improve recognition of BPSD in primary care and post diagnostic support, including targeting BME groups. Most research focused on mild-moderate dementia, and less is known about preventing crisis events or 'tipping point' that arise when family and carers can no longer live with the person with dementia's BPSD. Little is known about how structured anticipatory care from the point of diagnosis can reduce the incidence and prevalence of different types of BPSD for PWD living at home. There is also a need for a better understanding of BPSD issues, the appropriateness of interventions/services and how responsive they are to help improve outcomes for carers and PWD.

Patient and Public Involvement

This evidence synthesis was conducted in the context of the recognition that older people and their carers living at home/community who rely on primary care may have specific needs requiring appropriate care for a range of BPSD symptoms to improve both patient and carer outcomes. Patient and Public involvement in the study influenced the study in three ways. The original design and scope of the study, recruitment of people to the interviews and focus groups (FG) and the discussion and plan for the dissemination of the findings. The focus of this study was on managing behavioural and psychological symptoms of PWD (BPSD) and their carers. We reviewed a substantial body of

evidence on non-pharmacological interventions over a 14 year period, the experiences of PWD and their family carers and we involved stakeholders throughout the process to ensure that the recommendations developed from this study reflect the priorities and experience of PWD, their family and health professionals/service providers (SP).

There is a lack of clarity around definitions of BPSD related symptoms and approaches to effective management. The focus of the project and the review process were therefore informed by engaging stakeholders. The project has taken an 'elastic' definition of BPSD for community dwelling older people and their carers. The findings from this project are therefore important to older PWD exhibiting a range of these symptoms, their carers who deal with them and the health professionals and SPs and might be helpful in discussions with those commissioning services. Given the known limitations of some of the evidence it has been useful to incorporate expert review and comment as integral to the review process to optimize learning and consolidation of what is known for PWD living at home.

Stakeholder involvement

Engaging stakeholders at all stages of the project has grounded our review in the experiences of service users and local SPs. Before we began the review process, we held a preliminary stakeholder meeting with around 30 delegates from a wide range of backgrounds, including the Public Involvement in Research Group, carers, carer support services, voluntary organisations (e.g. Alzheimer's Society) Hertfordshire County Council, home care services, older people's services, those involved in the diagnosis and assessment of BPSD, and those offering support to PWD in the community and SPs, Hertfordshire Partnership NHS Foundation Trust (HPFT) (health professionals and SPs). They were identified and recruited through Public Involvement in Research Group PIRG, Research Management Group's established links with Age Net, Alzheimer's Society, carers groups, HPFT, Hertfordshire county council and with other research networks (e.g. Essex and Hertfordshire CLRN Age, Ageing specialty group (CG-chair, East of England, Primary Care Research Network, N. Thames).

The purpose was to discuss issues and concerns around BPSD management specifically for people living at home. It helped to understand how BPSD is defined/described and inform the focus of this project by highlighting what is important to consider when supporting people experiencing BPSD and their carers and informed the review process. At the end of the initial mapping of the broad evidence base, we involved service users and providers, professionals and voluntary organisations, in interviews and FGs to discuss the broad evidence and to help prioritise key issues for an in-depth systematic review. Service users were recruited through memory clinic (HPFT), Alzheimer's Society, community engagement officer.

Once preliminary findings were available, we held stakeholder FGs and interviews with PWD exhibiting BPSD and their carers. We also held FGs which included SPs from primary care, health professionals, commissioners, voluntary organisations, (e.g. Alzheimer's Society, Carers in Hertfordshire) to consider and comment on the review findings. We tailored the format of FGs and interviews to the different participants. Groups for SPs and health professionals, and carer representatives began with a presentation of some of the key results from the qualitative and quantitative review findings, and used as the basis for the subsequent discussion. For carers and PWD results from the study were presented in a more informal way but were still used as a guide for the discussion. These discussions, whilst supporting the overall review findings, also highlighted a number of evidence gaps, and gave useful pointers for practice and research, particularly around the

need for timely recognition of BPSD and early intervention, availability of appropriate information around BPSD in primary care and post diagnostic interventions and support for BPSD management. Much support is provided by informal family carers and the impact of BPSD is huge on both PWD and carers. Their involvement with professionals to meet their needs around managing BPSD, planning carer training programmes, improving carer-patient-professionals' interactions are important in developing support that matches the users' characteristics and preferences, identifying what is important at which point of dementia trajectory, including Black and Minority Ethnic populations.

Project advisory/steering group

The project was overseen by an advisory group that met three times over the course of the study with email communication of research progress. The group included a former dementia carer, representative from the Alzheimer's society, carer (Carer in Hertfordshire, Cross roads), commissioner, SPs, health professionals including clinicians involved in dementia care (Hertfordshire Partnership NHS Foundation Trust, North Essex Partnership NHS Foundation Trust), GP (East and North Hertfordshire), carer development worker, and senior academics with expertise in the project area.

They have had the opportunity to comment on the study protocol and analyses, and be involved in interpreting the project findings. They have helped in planning stakeholder and user involvement identifying suitable participants for interviews and FGs, and will be involved in the dissemination of findings, to ensure study findings are available to all potential audiences, including briefing papers and workshops targeting different groups (GPs, community nurses, carers and support groups, Alzheimer's Society, commissioners) to enhance understanding of BPSD in community settings and service recommendations.

Lessons learned

Given the complexity of BPSD management, involving stakeholders in developing questions, addressing key concerns and validating findings for local applicability is very valuable. However, this approach has required considerable investment in developing links with local memory services, dementia cafe's, carers' groups, commissioners, primary care professionals, carer development workers and various voluntary organisations. We attended support groups for PWD and their carers, conducted home visits and attended meetings with clinicians to recruit suitable people who exhibit BPSD for interviews/FGs.

Next Steps to Patient Benefit

Likely implications for practice

One of the priorities from the National Dementia Strategy for dementia care stresses the importance of community based services to support people at home and their carers to improve their outcomes. Whilst improving dementia services is an important local priority, managing behavioural and psychological symptoms (BPSD) for people living at home is complex and many only become aware of care needs following a crisis, and may have little understanding of how best to provide support, especially in the early stages..

Our comprehensive review has provided us with an up to date evidence of more relevant material specifically for community dwelling people (not in care homes) on what is known about types of interventions and their effects as well as service user experiences. We have also examined data

from interviews/focus groups with PWD, carers, service providers and commissioners. It provides a benchmark for future research, what interventions show most promise and demonstrates the importance of practitioners working closely with carers to achieve improved outcomes.

Our collective findings can be used to inform how professionals, including GPs improve recognition and diagnosis of BPSD and plan intervention at an early stage of dementia and provide accessible appropriate and timely information about follow-up services to help minimise BPSD and reduce carer burden. Developing a shared language on BPSD can be difficult, and research needs to take this into account.

Our findings support the local commissioning practice and Hertfordshire's Dementia Strategy which will provide a platform for the commissioners in planning and development of some carer support interventions around BPSD. The local strategy will focus on BPSD as a key issue, implement and monitor the use of Triangle of care, involving carers with professionals to meet their needs around managing BPSD and identifying what is important at which point of dementia trajectory. Our findings will also help inform the development of culturally sensitive interventions, including assessing and meeting needs of BME groups, as engaging with carers from BME groups appears to be difficult.

We have identified a number of barriers and services need to address how to remove barriers and to better engage carers and PWD for example in planning carer education and training initiatives, improving carer-patient-professionals' interactions important for meeting user's needs.

Commissioners need to address the resource and financial barriers as appropriate, as the literature overall did not include full economic appraisals of interventions. Future research needs to address this so value-for-money can be assessed.

The study adds to the evidence base for practice in the following ways:

- Better coordination of care plans are needed (health and social care together with carers) and early assessment of BPSD even in situations where it is not perceived as posing a threat to the person with dementia staying at home
- Greater emphasis on signposting, the role of information, its appropriateness and timeliness and how to tailor its provision to the needs of the individual
- Community development partnership and engagement issues with minority populations
- Evidence supports the development of multi-faceted interventions that include carer education and training components, skills enhancement and training for coping strategies
- Training of health professionals is important as they may have a vital role in delivering interventions to improve outcomes. This provision to target BPSD management needs to be examined in practice.
- High level of care involvement in interventions, with carer support and coping strategies.
- The need for more comprehensive follow-up with carers and PWD on BPSD management, with emotional support and strategies and assessment procedures that are BPSD specific to reduce the likelihood of events or 'tipping points' that lead to transfer to institutional care

- Engagement of people with dementia in meaningful activities can be beneficial; Sensory enhancement can relieve BPSD symptoms, and mentally stimulating activities can reduce agitation, but larger high quality studies are required
- An accessible health care/social service professional (e.g. key worker for continuity of support) able to provide practical information and support could contribute to the relief of carer burden

Although there is a large body of evidence around interventions which deal with people who present with BPSD and distress, the qualitative data addresses the escalating nature of BPSD, which needs to be considered along the dementia trajectory. Research relates to people who are supported by a family carer, most commonly a spouse and research on BME groups and those who live alone is under-reported. Different people will have different service needs at different points on the dementia trajectory. For example some people would like to initiate contact with appropriate services at the time of need (but are unaware of what is available) whereas others may be reluctant to get help due to denial or confusion.

The needs of PWD around the diverse range of BPSD related symptoms and the carers in relieving their stress and burden related to difficulties in managing these may be different and adequately meeting the needs of both is challenging for service providers. Some limitations include mixed quality of studies, considerable heterogeneity in interventions and outcomes and unknown cost implications. Interventions usually included BPSD management as one component of the overall complex intervention; however, we have attempted to identify key characteristics of effective multi-component interventions and from qualitative data included to help inform research and practice.

Next steps to ensure patient benefit locally and more broadly

We will disseminate evidence briefings to a number of local service providers and commissioners via the advisory group. Research team members contribute to the local dementia strategy group. A detailed report will be available on the University of Hertfordshire website.

Publication of our findings in journals and at conferences should help prevent duplication of unnecessary research on this complex and distressing topic. It identifies evidence gaps including examining components of multifaceted interventions that contribute to effectiveness on outcomes, economic appraisals, improving access to BPSD support interventions at all stages of dementia, research on BPSD management in BME groups informing a culturally tailored intervention and its evaluation.

The project has been instrumental in targeting future research. We have proposed a research doctoral fellowship (CLAHRC) around carer engagement approach for services supporting PWD as a model of care to lead to better care both for people experiencing BPSD and their carers. The research would seek to examine how carers and PWD are currently included in care provision for people presenting with BPSD, and experiences of health professionals in using the triangle of care to support their needs.

We have obtained funding from NIHR HTA around a realist synthesis managing the care of both dementia and diabetes, as well as the accompanying behavioural and psychological symptoms of dementia, which is a big challenge for carers (NIHR HTA Project: 13/138/03)

The next steps to ensure patient benefit should involve the development and evaluation of interventions, particularly those relating to improved recognition and diagnosis of BPSD and post-diagnosis interventions to prevent the tipping point, as well as carer education and training working with professionals along the care pathway.

Acknowledgements

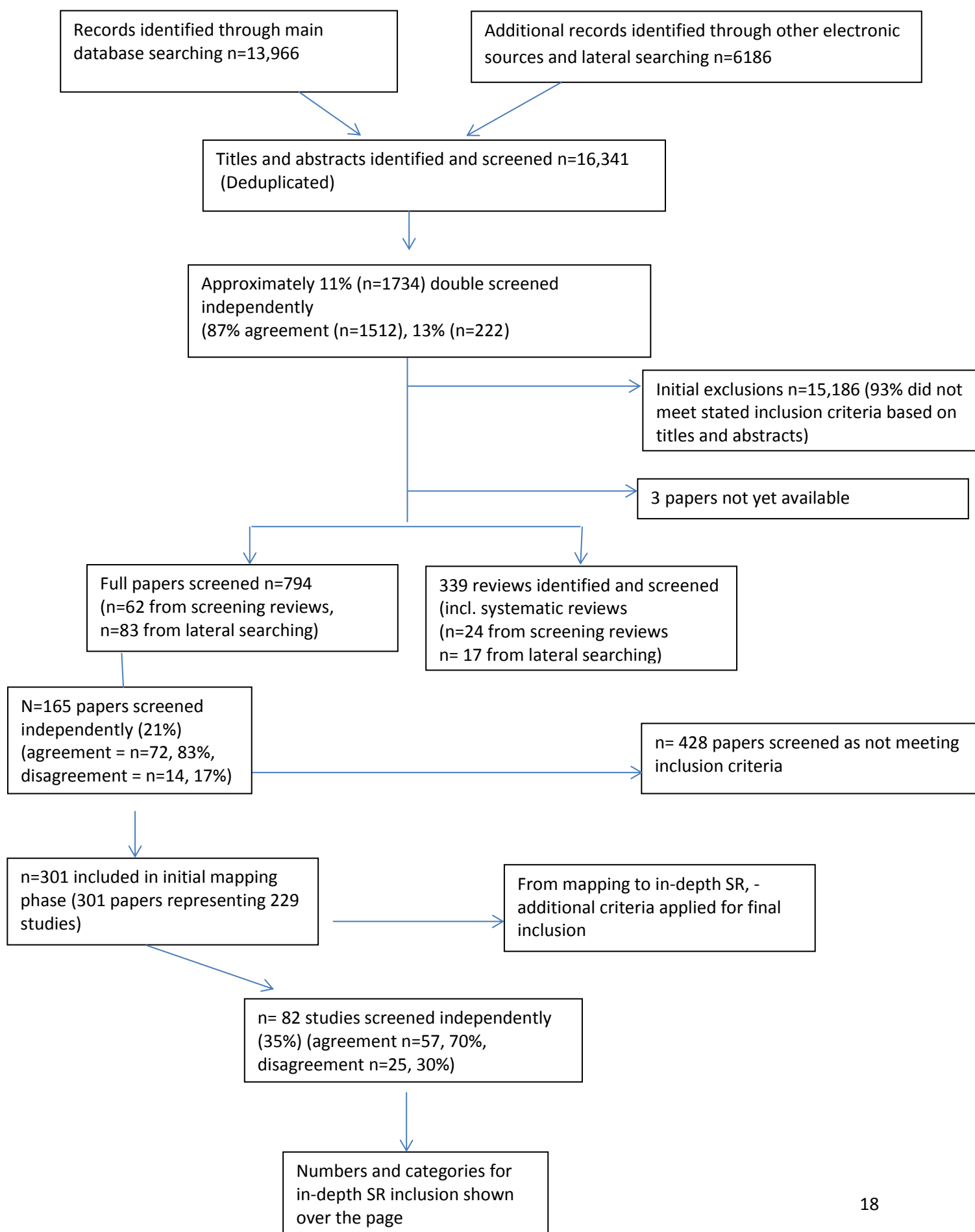
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Box 1. Example of Search Query

All studies were identified by computerised searches of PubMed, Embase, CINAHL, PsycInfo, AMED, HMIC, BNI, HEALTH BUSINESS ELITE, Scopus and Web of Knowledge (Web of Science). In addition we searched the Cochrane Library (including Cochrane Central Register of Controlled Trials (CENTRAL), Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects, Health Technology Assessment, Economic, Systematic reviews, Trials, Method, Techno. The following search query was used for the PubMed searches* (October 2012, updated March 2015): (dementia[ti] or Alzheimer*[ti]) AND (activities of daily living OR acupuncture OR animal-assisted OR aromatherapy OR art therapy OR Behavior Therapy OR biofeedback OR Breathing Exercises OR calligraphy OR cognitive-behavior OR cognitive therapy OR cognitive stimulation OR Combined Modality Therapy OR complementary therapies OR counseling OR creative therapy OR dance OR dance therapy OR day care OR Diet, Sodium-Restricted OR Diet, reducing OR Diet therapy OR domestic OR Electric Countershock OR Electric Stimulation Therapy OR electroconvulsive OR exercise OR exercise therapy OR family therapy OR group therapy OR hypnosis OR integrative OR interview therapy OR Life style OR massage OR music therapy OR occupational therapy OR Patient Education OR Phototherapy OR Physical Fitness OR physical therapy modalities OR physiotherapy OR psychotherapy OR psychosocial OR psycholog* OR complementary OR reality orientation OR recreation therapy OR rehabilitation OR relaxation OR relaxation therapy OR reminiscence OR respite care OR Sensory art therapies OR Self Care OR sleep therapy OR support OR Transcutaneous Electric Nerve Stimulation OR walking OR non-pharmacolog* OR nonpharmacolog* OR non-drug OR nondrug OR multicomponent OR multifaceted OR multi-factorial OR intervention OR rehabilitation OR complex OR alternative) AND (caregivers OR community OR community Health Services OR community health planning OR Community Health Services OR Community Health Nursing OR Community Health Workers OR community living OR community nursing OR community dwelling OR community-dwelling OR day care OR extra care housing OR Home Care Services OR home health care OR "home nursing" OR HOUSING-FOR-THE-ELDERLY OR Intermediate Care Facilities OR non-institutionalised OR occupational therapy OR Residence Characteristics OR sheltered housing OR Social Support OR carers OR dwelling) *Search terms were adapted for other databases.

Figure 1: PRISMA Flow chart of all papers and studies.



From mapping of broad evidence to inclusions for in-depth systematic review

Numbers reflect initial and updated searches; January 2000- May 2014, with additional lateral searches on key authors October/November 2014:

RCT's

- a. RCT's with interventions delivered to people with dementia, dyads and carers which aimed to address BPSD (albeit as one component of the intervention), n=68 studies-included as a priority
- b. RCT's with interventions delivered to people with dementia, dyads and carers which did **not** specifically aim to address BPSD, but measured BPSD relevant outcomes (these have not been synthesised, as outcomes are likely to be secondary, but an overview will be available to include in publications) n=22
- c. Non-randomised studies aiming to address BPSD, (for people with dementia, dyads, carers) n=19 (not synthesised as 68 RCTs provided a huge workload). An overview of these will be available to include in publications

Synthesis

RCTs for people with dementia, carers and dyads which aimed to provide BPSD related interventions and measured relevant outcomes (n=68). They provide the evidence base included in this report:

Total included: 68 studies (115 papers) plus 4 Qualitative studies (6 papers related to 4 RCTS)

- **People with dementia (people with dementia);** (n=7 studies, 9papers)
- **Dyads (People with dementia and carers)** (n=24 studies, 44 papers)- plus 1 qualitative related study
- **Carers** (n= 37 studies, 62 papers)- plus 4 qualitative related studies (6 papers)

Qualitative

Qualitative studies which relate to interventions aimed at BPSD and/or helping carers and people with dementia to deal with BPSD; n= 51 studies, 53 papers, of which n=24 were contextually rich, and were examined an in-depth analysis; n=29 were fair to moderate relevance to BPSD, and an overview of thematic analysis was conducted

List of references to included studies- See supplementary tables

BPSD project 2015

Reference List of all included studies (and related papers)

Quantitative (RCTs and related papers)

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