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Behavioral and Psychological Symptoms of Dementia: An Overview of Theoretical Frameworks and Associated Non-Pharmacological Treatments for BPSD

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Abstract

Background: Behavioural and Psychological Symptoms of Dementia (BPSD) such as agitation and aggression are core symptoms of dementia and affect almost everyone with the condition. Such symptoms cause distress to the person with dementia and their caregivers and have also been found to predict early institutionalisation as well as death. Historically, BPSD have been managed with medication, typically using anti-psychotic drugs. However, recent data show that anti-psychotic medications increase mortality and the risk of stroke in people with dementia. On the other hand, non-pharmacological interventions such as sensory manipulation, psychological therapies and providing training and psychoeducation for caregivers, present more encouraging results. Consequently, there is a need to explore the potential impact of non-pharmacological interventions on BPSD.

Key words: : BPSD, dementia, non-pharmacological treatments.

Introduction

Life expectancy is increasing globally, and is expected to continue to rise, especially in industrialised societies. This is resulting in an ever increasing dementia prevalence world-wide, with 4.6 million new cases being diagnosed each year and a prevalence that is expected to double between 2001 and 2040 (1).

Over 46 million people live with dementia worldwide and this number is estimated to increase to 131.5 million by 2050 (2). Alzheimer's Society Report (2014) (3) indicates that there are 850,000 people currently living with dementia in the UK. It also claims that 163,000 new cases of dementia occur in England and Wales each year, which means a new case arises every 3.2 minutes. Approximately 6% of people aged over 65 years have some form of dementia (4), with the population prevalence rising to 20% in those aged over 80 years (5).

The Impact of Dementia

The cost of dementia to the economy is immense. The Dementia Report (2014) (3) reveals that dementia costs the UK economy about £26 billion a year, which is more than the cost of cancer and heart disease combined. The global cost is even more prominent being estimated as US \$818 billion in 2015, and a trillion dollars by 2018 (6). As a result, dementia has been described

as “the greatest medical challenge of the 21st century» (7).

Investments in dementia research, however, remain relatively modest. In the UK, the combined government and charitable investment in dementia research, in 2010 was 12 times lower than spending on cancer research. Over £590 million is spent on cancer research each year, while just £50million is invested in dementia research.

There are 6.5 million people in the UK who provide unpaid care and support to older people with dementia (8). This number is predicted to reach 9 million by 2037 (9). According to the Dementia Report (2010) 25 million people or 42% of the UK population know someone close to them who has been diagnosed with dementia. The Alzheimer's Research Trust (2010) reports that 1.4 million of carers provide more than 50 hours per week unpaid care, thereby, saving the UK economy £8 billion per year.

Caring for people with dementia comes at a considerable personal financial, physical, mental and psychological price for the carers. Carers of people with dementia experience more physical and mental health problems (10, 11) and get more distressed (12, 13) when compared to their counterparts who look after older people without dementia. Despite the fact that carers bring huge savings to the economy, 75% of them report that they are worse off financially as a result of

caregiving (14). Carers report reduced income or working hours, missing out on opportunities for promotion, or being forced to give up work, as a result of their caring responsibilities (15).

Behavioural and Psychological Symptoms of Dementia

Behavioural and psychological symptoms of dementia (BPSD) are also known as neuropsychiatric or non-cognitive symptoms, are common and distressing features of the condition. As highlighted in Table 1, psychological symptoms can include anxiety, depressed mood, hallucinations and delusions. Behavioural symptoms refer to aberrant motor behaviour, verbal and physical aggression, screaming, restlessness, agitation, swearing, wandering, apathy, culturally inappropriate behaviours, disinhibition and hoarding (16). Unlike cognitive functioning of people with dementia that progressively deteriorates, BPSD symptoms typically fluctuate over the course of dementia (17, 18).

Phenomenology, Prevalence and Incidence of BPSD

The term ‘Behavioural and Psychological Symptoms of Dementia’ was introduced in 1999 by the International Psychogeriatric Association (IPA) who has been at the forefront of raising awareness about BPSD.

It is estimated that over 90 percent of people with dementia are likely to experience BPSD such as changes of personality and behaviour (19, 20) and sleep disruption (21). People with dementia are four times more likely to experience BPSD than older adults without dementia (22). Prevalence estimates for BPSD vary due to heterogeneity of population sample studied, in relation to diverse settings, type of dementia, different study designs, study sample size, different instruments used to measure the symptoms and the different definitions used for BPSD (23–27). Such estimates suggest that the prevalence of BPSD is more common in nursing homes than in community settings (28).

The development of BPSD is associated with a worse prognosis and faster rate of dementia progression (29). Untreated BPSD brings about a reduction in the quality of life for the person suffering from the condition and causes significant distress (26, 30, 31). Treating BPSD symptoms, can have a reparative impact on functional impairment, through reducing patient

Symptoms	
Aggression	Screaming
Verbal	Cursing
Physical	Agitation
	Hitting
	Biting
	Kicking
	Scratching
	Grabbing
Non-aggressive behavioral symptoms	
Verbal	Repetitive questioning
	Complaining
Physical	Wandering
	Pacing
	Hoarding
	Rummaging
	Hiding
	Taking other people’s belongings
	Shadowing
	Resistance to care
	Intrusiveness
	Mannerism
Thought and perception	Delusions
	Hallucinations
	Illusions
	Misperceptions
	Mania
Affect-Mood	Depression
	Anxiety
	Apathy
	Irritability
	Elation
	Persecution
Sleep disturbances	Insomnia
	Increased daytime napping
	Sundowning
Sexual	Hypo-sexuality (inhibited sexual excitement)
	Hyper-sexuality (increased sexual urges)
	Sexual disinhibition
Appetite	Poor food intake
	Hyperphagia (excessive hunger)

Table 1. Common behavioural and psychological symptoms of dementia

and carer distress and improving quality of life.

BPSD symptoms increase carer stress (32) and have a negative effect on their quality of life (33). Behaviours that challenge carers especially depression and low-mood are reported to have a consistent and powerful negative impact on the psychological health of carers (34). Behavioural and Psychological Symptoms of Dementia cause distress for carers and can contribute to the breakdown in care at home and lead carers to transfer the care of the person with dementia to a care home (35–38). For instance, the increased burden that is placed on the carer in relation to specific BPSD symptoms such as sleep disturbances (i.e. nightly restlessness and wandering) have been found to predict the relocation of care to nursing or residential homes (39, 40).

Untreated BPSD can also cause stress to nursing staff in residential facilities (41, 42) and increase financial costs (30, 43, 44).

Aetiology of BPSD

Different theoretical frameworks have been proposed to explain the aetiology of BPSD. These theories are divided into two major groups, neurobiological and psychosocial, and have driven the development of a variety of distinct interventions for BPSD.

The Neurobiological Theories of BPSD

The neurobiological/genetic theories of BPSD are predominant within medicinal research and practice, and assert that BPSD are the direct cause of cognitive decline, brain dysfunction, imbalance of neurotransmitters and genetic characteristics (45). Boyle and Malloy (2004) claim that apathy is triggered by an interaction between cholinergic deficiency and neuropathological changes in frontal brain regions. Agitation and psychosis are reported to be specifically correlated with a high burden of neurofibrillary tangles (47, 48).

The Neurobiological Theories of BPSD

Cohen-Mansfield (2000) (49) has proposed three psychosocial models of BPSD:

- The unmet needs model
- Learning/behavioural model
- Environmental vulnerability/reduced stress-threshold model

The Unmet Needs model suggests that the dementia process affects both the ability of the person with dementia to use the environment

appropriately to meet their needs and their ability to communicate their needs effectively (105–107). The interaction of such impairments with longstanding habits, personality, physical and mental states and unfavourable environmental conditions, can give rise to BPSD.

The Learning/Behavioural model proposes that BPSD develop as the direct result of conditioning. The basis of conditioning suggests that a reward which follows a particular response, acts as a reinforcer and increases the likelihood that the response will be repeated. For example: understimulation in a nursing home (bored, lonely) -> triggers agitation in a person with dementia -> staff engage more and try to calm and pacify the resident. While this may fulfil the social need of the person with dementia, the attention received by care staff reinforces agitated behaviours.

Lastly, the Environmental Vulnerability/Reduced Stress-Threshold model suggests that a person's needs and abilities need to match the environmental demands (105). This model maintains the decreased level of competence of people with dementia, is likely to increase the likelihood that they will be disturbed by the environment. Therefore, environmental stimuli that are inappropriate and exceed the individual's threshold for tolerating stress, result in negative mood and challenging behaviours (BPSD).

The three psychosocial models described above may be complementary and are not mutually exclusive. Different models may also account for different BPSD symptoms in different individuals.

Treatments for BPSD

Conventionally, a pharmacological approach has dominated the clinical management of BPSD. Common forms of treatments include mood stabilisers, anxiolytics, hypnotic and antipsychotic medications and more recently, cholinesterase inhibitors. Antipsychotic medications (e.g. haloperidol, risperidone, olanzapine) have been overly used to manage behavioural problems such as agitation and aggression. However, there are long-standing concerns that treating aggressive behaviour with pharmacological methods suppresses behaviour without addressing the cause (50, 51).

Use of antipsychotics in dementia increases the likelihood of stroke and premature death, leading health authorities in the United States (52) and the UK (53) to issue caution to clinicians, recommending that the use of such

drugs in the care for dementia should be avoided (51, 54). In the UK, the NICE/SCIE guidelines encourage clinicians to treat BPSD with non-pharmacological methods in the first instance, unless the patient is severely distressed and there is an immediate risk of harm to themselves or others (55). Long-term psychosocial strategies may be a better way to achieve the best quality care possible for people with dementia and those whom support them. For this reason, non-pharmacological alternatives are now being considered as first-line management of BPSD (56).

Non-pharmacological interventions for BPSD

The growing recognition of the importance of BPSD symptoms and the rising concern regarding their treatment with antipsychotic drugs have triggered a surge of interest in developing and applying non-pharmacological interventions as treatments for BPSD. Table 2 presents our summary of non-pharmacological interventions for BPSD. The main headings represent the category under which individual interventions have been included. Most of the individual therapies may be categorised under more than one heading, for example reduced sensory stimulation can be classified as sensory manipulation as well as environment manipulation and social contact. However, for ease of description individual interventions have been categorised under one heading.

Sensory manipulation treatments are primarily used with people with moderate to severe dementia and have been focusing on both stimulation enhancement and reduction. Stimulation enhancement approaches have been used to provide meaningful stimulation, reduce anxiety/agitation and improve mood and are based on the 'unmet needs' and 'environmental vulnerability' models, which propose that BPSD may result from periods of sensory deprivation (57). Massage therapies have included hand massage with essential oils (58–60), electrical nerve stimulation (61) and craniosacral therapy¹ (62). All these studies, apart from Scherder et al. (1995) have indicated decrease on agitation, wandering and fidgety behaviours, however, they are quite small with samples varying from 14–30 participants and the methodologies used are not robust (not blinded, no control group) (63).

- Aromatherapy involves the use of essential oils such as lavender, thyme and melissa

(lemon) balm for treatment of agitation in people with dementia. These oils have been applied in different ways such as by diffusion in communal areas (64), bedside diffusers (65), applied to the skin (66) and as sachets (67). Most of these studies have reported significant reduction in agitation and excellent compliance with the intervention (68). The study from Ballard and colleagues (2002) is a randomised controlled trial (RCT) that reported not only significant reductions in agitation but also excellent compliance with the intervention. However, the intervention itself was more than just aromatherapy as it also involved increased social contact whereby Melissa balm was applied twice a day on participants' faces and arms, which may also be considered as massage. Therefore, the benefit of aromatherapy is still under investigation and it has been reported as one of the fastest growing complementary therapies (69, 70).

- Music interventions have been quite heterogeneous, ranging from listening to music for relaxation and anxiety reduction (71, 72), during mealtimes (73, 74) or bath-times (75), to dancing, singing, playing musical instruments, or participating in composition and improvisation sessions (57, 76, 77). All of the above studies reported some benefits in terms of decreased agitation, reduction of aggressive behaviours and greater positive engagement. The main disadvantage of music intervention studies is that most of them have very small sample sizes (ranging from 10–46 participants); have employed within-participants experimental design; and use direct observational methods which are susceptible to rater bias and Hawthorne effect. Therefore the chance of obtaining significant results is reduced and the findings remain inconclusive (78). White noise (environmental sounds) has also been used to induce relaxation and sleep, and consequently reduce verbal agitation and wandering (79). Different music interventions feed into different psychosocial theories. For example listening for relaxation is based on the unmet needs and environmental vulnerability hypotheses; music use during bath and mealtimes is based on the above mentioned hypotheses as well as the learning/behavioural theory.
- Multi-sensory stimulation (MSS) or Snoezelen therapy, which is also considered as an emotion-oriented approach, combines

Sensory manipulation/ relaxation	Massage/touch Aromatherapy Music Snoezelen therapy/multi-sensory stimulation Decreased sensory stimulation Balancing arousal control excesses
Social contact	Pet therapy Reminiscence therapy Simulated Presence Therapy
Psychological therapies and emotion oriented approaches	Differential reinforcement (behavioural) Reality orientation/ Cognitive stimulation therapy Validation therapy
Environmental interventions	Stimulus control Signposting Use of Mirrors Wandering areas Enhanced environments Light therapy
Training and psychoeducation for carers	Educational programmes for staff and family carers
Structured activities	Recreational activities Physical activities (outdoor walks, Tai Chi, strength and flexibility training, etc.)

Table 2. Non-pharmacological therapies for BPSD

relaxation and exploration of sensory stimuli such as lights (e.g. fiber optics), sounds and tactile sensations (cushions, vibration pads). This therapy is usually delivered in dedicated rooms and sessions are tailored to individual needs (68). Multi-sensory stimulation is primarily used to reduce apathy in people with advanced dementia. Baker et al. (2001) examined the effects of MSS on 25 participants with moderate to severe dementia through an RCT and found significant reduction in dysphoric mood. However, when the same authors (81) ran a second, bigger trial (n=65) they did not find any significant differences between the control and intervention arms. The cost and complexity of MSS rooms can be a barrier to using them especially as evidence in their favour is not very robust.

- Decreased sensory stimulation interventions are based on the ‘reduced stress threshold’ model, which suggests that BPSD can result as a consequence of over or inappropriate stimulation. This approach has been applied in care or residential homes where the levels of

over-stimulation are higher than family homes. Two small studies (82, 83), with samples of 11 participants each, explored benefits of “quiet” interventions in agitation symptoms. Meyer et al. (1992) introduced a ‘quiet week’ which included turning off the television, lowering voices and reducing fast movement by staff at a day centre, and found a significant decrease in agitated behaviours. Cleary et al. (1988) took a more holistic approach by removing sources of stimulation such as TVs, radios and telephones as well as by manipulating the environment (introducing: smaller tables for eating and activities or neutrally painted walls), educating carers and training staff. These authors also reported decrease in agitation. Overall, there is limited evidence about the effectiveness of these interventions on BPSD.

Kovach et al. (2004) has taken a noteworthy approach to the subject of stimulation and its relationship to BPSD. These authors propose a model called Kovach’s Model of Imbalance of Sensoristasis, which describes the importance of keeping in balance sensory-stimulating and sensory-calming activities as this imbalance can give rise to or exacerbate agitation in advanced dementia. This model is consistent with Cohen-Mansfield’s (2000) environmental vulnerability/reduced stress-threshold model.

Social Contact

The next group of interventions include interventions that focus on real or stimulated social contacts and are based on the ‘unmet needs’ model of BPSD. Several studies suggest beneficial effect of pet therapy on agitation and verbal aggression (85–88).

- Reminiscence therapy (RT) uses materials (e.g. old newspapers, photographs and household items), music and art to stimulate memories and enable people to relive past experiences that are highly significant to them. This approach was originally but unsuccessfully utilised as an intervention for improving cognitive symptoms of dementia, but it has been shown to improve level of psycho-social wellbeing of people with dementia (Brooker & Duce, 2000; Lai, Chi, & Kayser-Jones, 2004; Woods, Spector, Jones, Orrell, & Davies, 2005). Reminiscence therapy is flexible and can be adapted to groups as well as individual needs. However, there is limited evidence of a significant impact of RT in BPSD (Woods et

al., 2005).

- Simulated presence therapy is grounded in the unmet needs and environmental vulnerability theories and entails use of videos or audio recordings of family members sharing conversations and memories with the person with dementia. This intervention has been used in care and residential homes. Two studies have reported reduction in physical and verbal agitation and greater frequency of happy expressions during treatment, however, these benefits do not seem to last beyond exposure time (92, 93).

Psychological therapies and emotion oriented approaches

- Differential reinforcement aims to reduce or eliminate maladaptive behaviours by using positive reinforcement in a structured way to increase desirable behaviour and is based on the 'learning/behavioural model'. Rogers et al. (1999) applied behavioural rehabilitation to reduce disruptive behaviour in nursing home residents with dementia. Doyle and colleagues (1997) also used reinforcement of quiet behaviour and environmental stimulation to decrease noise-making in 12 long-term-care residents with severe dementia. There have not been any reports of more recent interventions of differential reinforcement.
- Reality orientation (RO) is based on the idea that impairment in orientation and confusion prevent people with dementia from functioning well and is supported by the environmental vulnerability and the unmet needs models. RO facilitates re-orientation through: reminding people with dementia of facts about themselves; and through environmental manipulation (such as using signposting, clocks, calendars, newspapers, television, pictures, personal belongings). The efficacy of RO has been criticised by several authors who found RO classes non-efficacious (96); with little long-term effect (97); or argued that RO can have a negative effect on mood through reminding people of their prognosis (98, 99). Dietch and colleagues (1989) claimed that insensitive use of RO through incessantly correcting and challenging people with dementia could result on demeaning and confrontational experiences for this vulnerable population. However, more recent reviews (Spector, Davies, Woods, & Orrell, 2000; Spector, Orrell, Davies, & Woods, 2001)

have been quite favourable to RO and its outcomes. In fact it seems as though, after a loss of interest for this approach in the nineteen eighties, interest in RO has been reawakened (Spector et al., 2001; Woods, 2002) under the new term Cognitive stimulation therapy (CST).

- Cognitive stimulation therapy, unlike RO, is grounded in person-centred care (104) and its key principles are to appropriately and sensitively use multi-sensory stimulation to re-orient people with dementia and strengthen relationships with carers (Spector, Orrell, & Goyder, 2013). This approach is predominantly used in group of patients with mild to moderate dementia, as participants need to be able to carry out meaningful conversations and participate in group activities.
- Validation therapy (VT) is based on the Rogerian humanistic psychology argument that BPSD symptoms are strategies used by people with dementia to avoid stress, boredom and the painful reality of their condition (97). Validation therapists propose that empathic communication with individuals with dementia is essential rather than their orientation to the present. Neal and Barton Wright (2003) evaluated validation therapy through a Cochrane review and concluded that evidence about the efficacy of validation therapy is insufficient.

Environmental interventions

Environmental interventions include modifications of the factors that may cause or exacerbate BPSD such as: excessive noise (reduced stress threshold model), lack of routine (unmet needs model), inadequate lighting (environmental vulnerability model), confusing surroundings, and excessive demands by staff in residential settings (learning/behavioural model) (107). Many of these approaches have focussed exclusively on assisted-living facilities. Some of the environmental interventions include:

- Enhanced environments - Several non-randomised trials have investigated the effect of environment manipulation on agitation symptoms and exit-seeking behaviours of people with dementia in residential settings. Different approaches entailed: painting two dimensional grids on the floor in front of exit doors (108–110); painting murals over doorways (111); and placing blinds and cloth barriers over doors or door handles (112, 113). Chafetz (1990) concluded that the two-

dimensional grid is ineffective, however, the other authors reported on reduced exiting behaviours and ambulation.

- Wandering areas/ Removal of restraints – A few authors have criticised the reduced autonomy in institutionalised patients, and have argued that these settings exacerbate or even cause BPSD. Two studies found that unlocking exit doors in a residential home, and release from mandatory confinement in an acute unit reduced agitation as well as both physical and verbal aggression (114, 115).
- Light therapy – Light therapy has been utilised to improve circadian rhythms, which are impaired in people with dementia (116). This approach is supported by the ‘unmet needs’ model as it attempts to improve sleep (117, 118) and consequently reduce agitation (119, 120). The above studies have reported benefits on sleep and agitation, but other studies have reported no effect (121, 122). Overall, the support for this approach remains inconclusive as the reported studies are small non-RCTs (57, 123, 124).

Training and psychoeducation programmes for carers

This approach focuses on improving carers’ knowledge of dementia and BPSD, improving communication with people with dementia, and on providing potential management strategies for BPSD. Reduced agitation has been reported after training staff on communication skills (125), empathy (126), tailored and focused care (127–129). Psychoeducation interventions with family carers have also resulted in improved mood (130) and decreased or delayed institutionalisation (131, 132). All the above studies report improved outcomes immediately after the intervention, however this effect ceases not long afterwards, indicating that educational programmes should be of an ongoing nature rather than a one-off intervention (133).

Structured activities

- Recreational activities such as sewing, dancing, games, playing instruments have been reported to have a positive effect on agitation (134) and wandering behaviours (135, 136). These findings, however, are based on a small number of non-randomised studies.
- Physical activities include various types of physical exercises such as outdoor walks (137,

138), Tai Chi (139), strength and flexibility training (140), walking, cycling, chair based exercise (141).

Conclusions

Behavioural and psychological symptoms are some of the most common elements and signs of dementia. Their heterogenous aetiology is drawn from both neurobiological and psychosocial factors as well as environmental ones. Pharmacological approaches have dominated BPSD treatment plans during the past years, although concerns regarding the long-term impact on disease and mortality overall along with their role in targeting the actual causes rather than the symptoms themselves have frequently been raised. As such, most recently, alternative approaches, utilizing non-pharmacological interventions have gained increased attention with positive results. Sensory manipulation interventions, such as aromatherapy and decreased sensory stimulation, psychological therapies and emotion-oriented approaches, as well as training in communication and psychoeducation of the caregivers, present the most encouraging results. In addition, and in the same context, environmental interventions underline the importance of light therapy and enhanced environments approaches. Consequently, non-pharmacological interventions could potentially play a pivotal in BPSD management. They offer an individualized treatment plan free of pharmacological side effects while facilitating a strong interaction between people suffering from dementia and their caregivers with significant long-term impact. Despite the encouraging evidence, non-pharmacological interventions are still quite limited. Therefore, further research would be necessary to explore the full potential of those interventions on BPSD.

Conflict of Interest

We declare that we have no conflict of interest.

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