Exploration of non-pharmacological interventions in the management of behavioural and psychological symptoms of dementia

Nur Sabiha Md Hussin¹, BPharm, MPharm, Mahmathi Karuppannan¹, MPharm, PhD, Yogheswaran Gopalan¹, MPharm, PhD, Kit Mun Tan², MBBCh, MRCP, Shubashini Gnanasan¹, MPharm, PhD

¹Department of Pharmacy Practice, Faculty of Pharmacy, Universiti Teknologi MARA Cawangan Selangor, Selangor, ²Division of Geriatric Medicine, Department of Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia

Abstract

Introduction: Behavioural and psychological symptoms of dementia (BPSD) are considered integral parts of dementia. While pharmacotherapy is reserved for severe symptoms of BPSD, the associated adverse effects can be detrimental. Therefore, non-pharmacological intervention is recommended as the first line of treatment in the management of BPSD. This study aimed to explore the non-pharmacological approaches for the management of BPSD and the strategies and barriers to implementing them in secondary care facilities in Malaysia.

Methods: A qualitative study design was employed. Data were collected through observations and semi-structured interviews of 12 caregivers and 11 people with dementia (PWD) at seven secondary care facilities. Observations were written in the field notes, and interviews were audio-recorded and transcribed. All data were subjected to thematic analysis.

Results: Some personalised non-pharmacological interventions, such as physical exercise, music therapy, reminiscence therapy and pet therapy, were conducted in several nursing care centres. Collaborative care from the care providers and family members was found to be an important facilitating factor. The lack of family support led to care providers carrying additional workload beyond their job scope. Other barriers to non-pharmacological interventions were cultural and language differences between the care providers and PWD, inadequate staff numbers and training, and time constraints.

Conclusion: Although non-pharmacological approaches have been used to some extent in Malaysia, continuous education and training of healthcare providers and the family members of PWD is needed to overcome the challenges to their successful implementation.

Keywords: BPSD, non-pharmacological interventions, strategies and barriers

INTRODUCTION

Dementia is defined as an acquired global impairment of higher cortical functions, which affects memory, capacity to solve problems, perceptual motor skills, social skills, language and communication, and control of emotion.¹ In Malaysia, the incidence of cognitive impairment in older persons aged more than 60 years was 18.5% in 2012, with the percentage steadily increasing with age.² With rapid increment in the ageing population, dementia has become a serious concern for the society and the healthcare system. Behavioural and psychological symptoms of dementia (BPSD) are considered integral components of dementia, with more than 50% of people with dementia (PWD) experiencing BPSD.³ Disturbed perception, decline in emotional control or motivation, or a
change in social behaviour can manifest as emotional lability, irritability, apathy and worsening of social behaviour. The poor prognosis of BPSD has important implications for cognitive function, daily activities and quality of life of PWD. Behavioural and psychological symptoms of dementia can be distressing for PWD, their caregivers and healthcare professionals, leading to the placement of PWD in nursing care homes and secondary care facilities (the latter includes private nursing homes and special institutions that provide more complex and long-term care to PWD). Care of people with BPSD includes pharmacological and non-pharmacological management. In the early years, a wide range of pharmacological agents was used for the first-line management of neuropsychiatric symptoms for PWD. The prescription and administration of antipsychotics to control BPSD was prevalent in nursing homes. Recently, clinical benefits and risks in the use of aripiprazole, olanzapine and risperidone for the treatment of BPSD were reported by the Agency for Healthcare Research and Quality in the USA. However, due to their questionable efficacy and various adverse effects, including a high mortality risk, non-pharmacological interventions are being tried as the first-line approach for the management of BPSD. Non-pharmacological approaches could be delivered through psychotherapeutic methods, which include cognition-oriented (i.e. eality orientation, reminiscence therapy), emotion-oriented (i.e. supportive psychotherapy, validation therapy), behaviour-oriented (i.e. stimulus control, non-contingent reinforcement), and stimulation-oriented (i.e. recreational, art and crafts) methods.

Traditionally, the strategies for managing BPSD were mostly aimed at eliminating challenging behaviours with pharmacological approaches. Currently, there is a huge shift from this traditional approach to person-centred care, which is more effective in managing behavioural challenges. Although most of the previous studies highlighted the importance of personalising the psychotherapeutic approach for better behaviour management, they also suggested long-term systematic and continuous training or education with complementary clinical support for care providers to ensure a more comprehensive strategy for the management of BPSD. In addition, a caring environment with a conducive physical and social design for PWD has been shown to positively impact behaviour control. The emphasis for social contexts includes caregiver staff stability, the interpersonal relationship between the care provider and PWD, and development support for PWD.

Several barriers may impede the successful delivery of non-pharmacological interventions. Some of the well-recognised internal challenges are poor organisational arrangement (lack of systematic roles of health professionals in secondary care facilities), social factors (limited interactions of care providers with the residents), the technology used (lack of a recording and tracing system of residents’ behaviour and interventions given), and the physical setting of the facilities (lack of access to a mental health specialist for a thorough evaluation of the symptoms of BPSD). Meanwhile, external challenges include the refusal of family members to accept or acknowledge the behavioural issues of PWD in their families. There is also a tendency for family members to opt for medical therapies or a restraint approach rather than non-pharmacological interventions. In addition, a non-conducive environmental design (overstimulation of sensory stimuli from television, loud noises and roommates’ behaviours) may contribute to negative outcomes, even when non-pharmacological interventions are adopted.

Despite the availability of guidelines on the different types of non-pharmacological interventions, the current practices in the local settings are still lacking. Furthermore, incorporating successful non-pharmacological interventions requires a deeper understanding of the potential strategies and challenges associated with it. Thus, this study aimed to explore the current practice of managing BPSD and to identify the potential strategies and challenges in executing non-pharmacological interventions.

METHODS

Seven secondary care facilities for PWD — comprising two day care centres and five nursing homes in the urban area of Klang — were included this study, which was conducted from November 2019 to January 2020. In this study, caregivers referred to the care providers of any nationality, who are proficient in English or Bahasa Melayu and have at least 1 year of experience in caregiving for PWD. Only PWD with a diagnosis of mild or moderate dementia were recruited. The classification for severity of dementia was based on the section, ‘Scoring Frailty in People with Dementia’ in the Clinical Frailty Scale. Mild dementia was characterised by the inability to remember details of recent events even though there is recall of the event itself, repetitiveness in questions or stories, and some signs of social withdrawal. Moderate dementia referred to very impaired recent memory with good recall of past life events and the ability to perform personal care with prompting.

The research study was approved by the Research Ethics Committee of Universiti Teknologi MARA (ethics approval number: REC/360/18). The qualitative study involved the selection of interviewees using purposive and snowball sampling. The snowball sampling method was useful in recruiting participants with target characteristics through referral from existing study participants. A geriatrician (Tan KM) provided suggestions for eligible care centres according to the criteria. The founder or manager of each centre was approached to recommend the caregivers and PWD to be interviewed. Before the commencement of interview with PWD, a subject information sheet was provided to the legal guardian of PWD, and signed informed consent to participate was obtained from the caregiver and legal guardian of PWD.
A series of observations were conducted in seven secondary care facilities, where in-depth face-to-face interviews with 12 caregivers and 11 PWD were conducted. The observations were written in the field notes, and interviews were audio-recorded and transcribed. All interview sessions took an average of 10–20 min. Concurrent data analysis and constant comparison were done by continuously modifying the interview based on the interviewee’s response. Hence, the complex data could be synthesised in an inclusive and manageable manner. All the data were manually analysed through thematic analysis. Consequently, significant themes were identified after the transcripts were read line by line. Important codes were generated thematically and categorised into three main themes comprising both strategies and barriers. Subthemes were further identified and categorised under each main theme. Before the interview, verbal consent was obtained from each participant, and pseudonyms were used to ensure confidentiality and anonymity. None of the PWD appeared distressed and all the PWD were able to participate in the interviews.

RESULTS

The non-pharmacological interventions being practised in secondary care facilities included music therapy, exercise and motor rehabilitation, and cognitive games and activities. Other non-pharmacological interventions were reminiscence therapy, massage and touch therapy, arts and craft, acupuncture, pet therapy and coconut oil consumption.

Saturation of themes was achieved after interviewing 12 caregivers and 11 PWD. The 12 caregivers were from Asian countries, and the 11 PWD were Malaysians. The ten themes that emerged comprised strategies and barriers related to three main categories: person-centred care, social interaction and cognitive-oriented activities.

Category one: Person-centred care

Strategy: Understanding dementia behaviour

Most of the centres adopted the well-studied philosophy of person-centred care, where the care providers meticulously examined the personal experience of PWD and used this information as the basis before any intervention was implemented.

“At the beginning when we encounter them, we will inquire about their medical history, social history as we would want to know what makes them reach this stage. We can avoid some sensitive questions which can trigger them to become sad or angry.” (Akim, caregiver)

Strategy: ‘Give time to resolve’

‘Planned ignoring’ or giving time for behaviour to resolve has been a widely practised strategy in the care centres. Moreover, environmental adjustment as an antecedent strategy was also reported by the caregivers to have a significant role in coping with behavioural challenges.

“We just have to leave them alone for a while, let them release the anger and agitation inside them, then only we talk to them again. We cannot totally ignore them .... However, it’s very important to give time to them.” (Shuhada, caregiver)

“We think by mixing dementia people together is better as they would be in the same world, it’s easier for us to cater their needs....” (Amie, caregiver)

Barrier: Lack of training and skills

The interview revealed that PWD perceived that their voices were rarely heard, which led to feelings of dissatisfaction, as their needs were unmet. It also revealed that PWD preferred to engage in indoor or outdoor physical activities that involve social interaction and cognitive-oriented activities (such as learning a new language, spelling, reading and writing).

“I like ... some needlework ... Sewing...” (Chee See San, PWD)

“I can spell ... S-N-A-K-E. Snake. B-R-E-A-D. Bread....” (Gan Ah Wei, PWD)

The lack of training and skills of the caregivers was the main reason for incomplete execution of person-centred care.

“Only if the centre sends a representative to train the caregivers. It is at our own effort if we want to go for extra courses or classes.” (Shuhada, caregiver)

“I think we were well-trained with sufficient training and skills. We know how to prepare food, how to administer medicine to the patient, how to check the BP, how to check the sugar level....” (Aisha, caregiver)

“I think I have never heard of this Malaysian Clinical Guideline.” (Rahmat, caregiver)

“My friend who was already in this field always taught me how to care for dementia patients. He doesn’t have any certificate of professionalism on how to care for them. So, he taught me only based on his experience.” (Taripnan, caregiver)

Barrier: Inadequate staff numbers and time constraints

It was evident that personalised management was not carried out fully, as there was inadequate number of staff to meet all the needs of the residents. People with dementia require more attention compared to older people with intact cognitive function. More staff were needed when PWD started manifesting BPSD symptoms such as aggression. The staff needed to distract them from the triggering factor of BPSD, attend to them when they manifest BPSD and deal with the consequences of post-BPSD symptoms. This aspect was particularly highlighted by the caregivers:

“These dementia residents have more needs than normal elderslies. Sometimes, more than one of them act up at the same time. When I go to one patient, another one acts up and shows behaviours. That is why sometimes we just tie one patient while we go to entertain another.” (Taripnan, caregiver)
Category two: Social interaction
Strategy: Verbal and non-verbal communication

The results from the observation and interview sessions with PWD revealed their eagerness for social interaction. It was noted that some facilities were successful in creating meaningful conversations with PWD through interventions such as music therapy, cognitively stimulating games and activities, and pet therapy.

“If they are still aggressive, we just speak gently to them and never oppose whatever they said at that time. If they think that their children will pick them in the evening, we just have to agree with them even if it’s not going to happen, and use that modality to persuade them to go eat or change diaper.” (Venus, caregiver)

“We have to slow talk with them while making eye contact and body language. At that moment they will express their feeling, maybe they want something. From there, we are able to identify what is their need.” (Akim, caregiver)

Barrier: Communication barrier

Cultural misunderstanding between PWD and healthcare providers, who were predominantly expatriates, was yet another factor contributing to patient dissatisfaction and poor quality of care. It was also reported that language and cultural barriers impede successful social interaction with PWD.

“I changed her caregiver to be with the same race. As Indian prefers to be with an Indian to take care of them because they can talk in the same language.” (Gaya, caregiver)

“At the start, she speaks English but towards the end, she will start to speak Malay … so obviously I don’t understand her and I have to remind her to speak English.” (Venus, caregiver)

‘Elderspeak’ (i.e., secondary baby talk or infantilisation) is defined as features of communication using simple language or grammar with short sentences, slow speech, elevated pitch and volume, and inappropriately intimate terms of endearment.24 The caregivers interviewed indicated that ‘elderspeak’ is widely practised in long-term care facilities, although this method of communication was banned by one of the day care centres in our study. It is acknowledged that although ‘elderspeak’ was anecdotally reported to be beneficial,25 some have found it to be inappropriate or disrespectful when used during interactions with PWD.26

“Yes, we treat them as a baby and so far, none has become angry because we treat them like that. They in fact like it, I don’t know ... maybe they like the tone of our voice when we call them.” (Catherine, caregiver)

“The staff addresses each resident with politeness and respect by using their name and credentials such as Doctor or Professor. The staff speaks to them by normal communication, like an adult to adult communication.” (Observational notes)

Category three: External roles
Strategy: Multidisciplinary collaboration

Dementia is a complex syndrome involving cognitive, physical and emotional disturbances; thus, interventions from multiple specialties are required. This becomes one of the strategies in the care facilities. As reported by the caregivers, PWD had alliances with doctors since their primary enrolment into the care facilities. Family members of PWD were also engaged in decision-making for the appropriate care plan.

“Doctors and nurse often come. They will come this evening and check the patients, staff, rooms and sometimes they also check the facilities here.” (Venus, caregiver)

“I notify the relatives about the behaviour and how frequent it happened. Then the decision is from the relative or family member, it’s either they want to bring them to a private doctor, in house doctor or the geriatrician to start on medications.” (Yona, caregiver)

Barrier: Less supportive family members

Taking care of PWD is undoubtedly challenging for the family. Regardless of this, some families have positive attitudes, while others were less supportive in providing the best care for their loved ones, which caused a major challenge to caregivers of PWD.

“But some clients are very egoistic ... I don’t think they will take the tips and change according to our suggested plan and tips.” (Gaya, caregiver)

“But when the children come, they will talk about all the negative points and fight with the elderly. This makes the elderly depressed. Family unity is not there.” (Gaya, caregiver)

“She just ate but she forgot, and she tells her daughter that she did not eat. The daughter came and scolded me for not feeding her. I snapped a picture of her eating and ‘WhatsApp’ the daughter:” (Yona, caregiver)

Barrier: Responsibility outside the job scope

Family members and relatives placed high expectations on the caregivers to provide extensive services that were beyond the caregiver’s job scope. These included performing complicated and invasive tasks, such as inserting a bladder catheter. Lack of collaboration and understanding from the family members created not only extra roles, but also more stress and burden for caregivers of PWD.

“They don’t want to bring the mother to the hospital and refuse medication even though we give the options, so it’s like, ‘as long as we pay the monthly fee, then that’s it’...” (Shuhada, caregiver)

“Complicated task, such as putting in the catheter, I don’t really know how to do it.” (Taripnan, caregiver)

DISCUSSION

Well-recognised non-pharmacological interventions in the management of BPSD include music therapy, reminiscence therapy, acupuncture, touch therapy and cognitive activities,
and these have been extensively practised in the local context. Successful interventions require a systematic recognition of potential strategies and the barriers associated with them. The findings from this exploratory qualitative study are consistent with the findings from the literature, which showed improvement in BPSD when personalised approaches were incorporated.[29,30]

This study contributed to the area of person-centred care based on the voices of PWD. Our findings showed that when the needs of PWD are not completely unfulfilled, it could lead to manifestations of behavioural disturbances. Questioning the caregivers uncovered that the main reason for the above issues was lack of training and comprehensive education. The inability to grasp a wider context of personalised care might explain why some interventions seem to be ineffective in certain PWD. Kim and Park stated in their study that environmental consideration and social aspects are required for comprehensive execution of personalised care management, as these elements are fundamental in delivering non-pharmacological interventions.[31] Another study further recommended frequent and continuous education and training in multiple concepts or methodologies for improvement in tailored interventions. For example, care providers should be aware of the concept of need-driven behaviour (NDB) to recognise the key inducers of NDB (i.e. background condition of the disease and the related factors).[32] Structured approaches, such as the Dementia Care Mapping, Treatment Route for Exploring Agitation, and Describe-Investigate-Create-Evaluate methods, are also beneficial in aiding decision-making before delivering non-pharmacological interventions. However, these useful methods require standardisation of agreed guidelines nationwide for better management of BPSD, as well as to empower care providers and increase their competency.[33]

Collaborative care in shared decision-making was mentioned as one of the successful strategies in managing BPSD in the local setting. This finding is consistent with the recommendations made by Callahan et al.[14] that collaborative care should be practised due to the high reliability of strong evidence-based medicine. A systematic review also stated that 17% of failure in delivering non-pharmacological interventions was due to unsupportive family,[35] and therefore, long-term education and support by the family members are essential. In this study, the caregivers also complained about the lack of support from the family members, which became a limitation in incorporating non-pharmacological interventions. Responses from the caregivers indicated that ‘trust issues’ among family members was a major challenge that halted the caregiving flow. These findings are supported by a previous study that reported high rates of burden, social isolation, physical ill health and financial hardship as the roots of negative attitudes observed among family members.[136] This study, however, did not include the perspective of family members in dementia care; hence, similar exploratory research can be performed in future to address it.

In this study, PWD were actively engaged in conversations and were keen for social interaction during the interview sessions. However, this study was unable to ascertain whether their social needs were fulfilled; therefore, a future quantitative study in this area is highly warranted. However, it was also noted that some centres managed to engage the residents through activities and effective communication. A multimodal care or ‘Humanitude’ method suggested that a combination of verbal and non-verbal communication is highly effective in reducing BPSD, especially in long-term care facilities.[37] Another study further elaborated on the importance of communication between all stakeholders, and supportive relationships and environment in providing a holistic social interaction.[18]

There are limited findings on ‘elderspeak’ in the literature. Most caregivers in nursing homes perpetuated the practice of ‘elderspeak’, but this practice was strictly opposed by one caregiver from a day care centre in our study. Despite limited existing literature, most studies from the early years claimed that ‘elderspeak’ calmed challenging behaviours, increased cooperation in performing tasks,[38] provided warmth and increased succourance,[39] and improved sentence comprehension.[40] However, more recent studies concluded that ‘elderspeak’ was non-beneficial, as it was patronising, stereotyping, prejudiced and discriminating.[40,41]

There were two limitations in this study. First, several caregivers could not converse in English, and hence, the interview process took a long time. Second, some of the recorded interviews were excluded, as the information was not comprehensible. In future, the insights from family members should be included. More data could be obtained by carrying out a similar study in home-based settings or outside the urban Klang Valley area. The strengths of this study are that it included different nationalities of caregivers, which is a true reflection of the workforce in most nursing homes in Malaysia, and PWD were of the three main ethnic groups in Malaysia. Also, since a previous study did not include the voices of PWD,[42] this study was able to fill the gap. Meaningful conversations with PWD were achieved and their voices are projected in this study.

In conclusion, despite the availability of non-pharmacological management guidelines, the translation into practice was found to be unstructured and flexible, thus making the execution of the management ad hoc and non-standardised at the local level. A more holistic approach to tackle BPSD may include adapting strategies to successful intervention, identifying barriers and integrating PWD’s perspectives into dementia care.

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Conflicts of interest
There are no conflicts of interest.

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