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

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ABSTRACT

Introduction: Behavioural and Psychological Symptoms of Dementia (BPSD) are considered as integral parts of dementia. Whilst pharmacotherapy is reserved for severe symptoms of BPSD, the associated adverse effects can be detrimental. Therefore, non-pharmacological intervention is recommended to be the frontline in the management of BPSD. This study aimed to explore the non-pharmacological approaches for the management of BPSD including the strategies and barriers of 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 twelve caregivers and eleven 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 between care providers and family members was found to be an important facilitating factor. Hence, lack of family support led to additional workload, which were beyond the job scope of the care providers. Other barriers identified for non-pharmacological interventions were cultural and language differences between care providers and PWD, inadequate staff numbers and training, as well as time constraints.

Conclusion: Although non-pharmacological approaches have been conducted to some extent in Malaysia, continuous education and training for the healthcare providers as well as the family members of PWD are needed to overcome the challenges with regards 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, as well as control of emotion.⁽¹⁾ In Malaysia, cognitive impairment in older persons aged more than 60 years old was at 18.5% in 2012 and the percentage is steadily increasing with age.⁽²⁾ With the rapid increment in the ageing population, dementia becomes a serious concern for society and the healthcare system. Behavioural and psychological symptoms of dementia (BPSD) are considered as 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.⁽⁴⁾ The poor prognosis of BPSD has important implications for cognitive function, daily activities and the PWD's quality of life.⁽⁵⁾ BPSD can be distressing for PWD, their caregivers and the healthcare professionals; which may lead them to be placed in nursing care homes and other secondary care facilities.⁽⁶⁾ Secondary care facilities are facilities that provide more complex and long-term care to PWD, which include private nursing homes and special institutions.⁽⁷⁾

Care of people with BPSD include pharmacological and non-pharmacological management. In the early years, a wide range of pharmacological agents was used as the first-line management of neuropsychiatric symptoms for PWD.⁽¹⁾ The prescription and administration of anti-psychotics to control BPSD was high in nursing homes.⁽⁸⁾ 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.⁽⁹⁾ However, due to their questionable efficacy and various adverse effects which includes high mortality risk,⁽¹⁰⁾ non-pharmacological interventions are being tried as the first-line approach for the management of BPSD.⁽¹¹⁾ Non-pharmacological approaches could be delivered through psychotherapeutic

methods, which include cognition-oriented (i.e. reality 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).⁽¹²⁾

Traditionally, the strategies for managing BPSD were mostly aimed at eliminating challenging behaviours with pharmacological approaches.⁽¹³⁾ Currently, there is a huge shift from this traditional approach to person-centred care, which is more effective in managing behavioural challenges.⁽¹⁴⁾ 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.^(15,16) In addition, a caring environment with a conducive physical and social design for PWD has been shown to impact positively on behaviour control. The emphasis for social contexts includes caregiver staff stability,⁽¹⁷⁾ interpersonal relationship between care provider and PWD,⁽¹⁸⁾ as well as development support for PWD.⁽¹⁹⁾

Several barriers may impede the successful delivery of non-pharmacological interventions. Some of the well-recognized internal challenges are poor organisational arrangement (i.e. lack of systematic roles of health professionals in the secondary care facilities),⁽²⁰⁾ social factors (i.e. limited interactions of care providers with the residents),⁽²¹⁾ the technology used (i.e. lack of a recording and tracing system of residents' behaviour and interventions given)⁽²²⁾ and the physical setting of the facilities (i.e. lack of access to a mental health specialist for a thorough evaluation of the symptoms of BPSD).⁽²³⁾ Meanwhile, external challenges include the refusal of family members in accepting or acknowledging behavioural issues of PWD in their families. The tendency of family members to opt for medical therapies or a restraint approach rather than non-pharmacological interventions is also a sad reality.⁽²²⁾ Apart

from this, a non-conductive environmental design (i.e. overstimulation of sensory stimulus from television, loud noises and roommates' behaviours) may contribute to negative outcomes although there is provision of non-pharmacological interventions.

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 comprising of two day care centres and five nursing homes for PWD in the urban area of Klang were included in the study. The study was conducted from November 2019 to January 2020. Caregivers refer to the care providers from any nationality, who are proficient in English or Bahasa Melayu and with at least one year of experience in caregiving for PWD. Meanwhile, only PWD with a diagnosis of mild or moderate dementia were recruited. Participants with mild dementia were characterized as those who had forgotten the details of recent events, even though they could recall the event itself, exhibiting repetitiveness in their questions or stories and some signs of social withdrawal. Moderate dementia referred to participants with very impaired recent memory, although they could recall their past life events well and were still able to perform personal care with prompting. This classification of severity of dementia was based on the section on "Scoring Frailty in People with Dementia" in the Clinical Frailty Scale.⁽²⁴⁾

The research study was approved by the Research Ethics Committee of Universiti Teknologi MARA (Ethics approval number: REC/360/18). The present 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.⁽²⁵⁾ 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 selection of caregivers and PWD to be interviewed. Prior to the commencement of the interview with the PWD, signed informed consent to participate was obtained from the caregiver and the legal guardian of the PWD after the legal guardian had read the subject information sheet.

A series of observations were conducted in seven secondary care facilities where in-depth face to face interviews with twelve caregivers and eleven PWD were done. The observations were written in the field notes and interviews were audio-recorded and transcribed. All interview sessions took an average of 10-20 minutes. Concurrent data analysis and constant comparison technique were done by continuously modifying the interview based on the interviewee's response. Hence, the complex data could be synthesised in an inclusive way and manageable manner. All the data were manually analysed through thematic analysis. Consequently, significant themes were identified after reading the transcripts 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. Prior to the interview, verbal consent was obtained from each participant and pseudonyms were used to ensure confidentiality and anonymity. None of the participants with dementia appeared distressed and were able to participate in the interviews.

RESULTS

The findings revealed the current non-pharmacological interventions being practised in secondary care facilities. They include music therapy, exercise and motor rehabilitation as well

as cognitive games and activities. This is followed by reminiscence therapy, massage and touch therapy, arts and craft, acupuncture, pet therapy and coconut oil consumption.

Saturation of themes was achieved after interviewing twelve caregivers and eleven PWD. The twelve caregivers were of various nationalities from Asian countries and the eleven PWD were of Malaysian nationality. There were 10 themes comprising of strategies and barriers related to the same categories, namely person-centred care, social interaction and external roles.

Category One: Person-Centred Care

Strategy: Understanding Dementia Behaviour

The non-pharmacological interventions in most centres adapted the well-studied philosophy of ‘person-centred care’ where the care providers meticulously examined PWD’s personal experience and used this information as the basis before implementing any intervention.

“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 with PWD revealed that their voices were less heard, which resulted in dissatisfaction due to their unmet needs. It also revealed that PWD favoured engagement in indoor or outdoor physical activities, which involved social interaction and cognitive-oriented activities (i.e. 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 were the main reasons 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 were inadequate numbers of staff to meet all the needs of the residents. PWD 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 need 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 mentioned by the caregivers.

“These dementia residents have more needs than normal elderlies. 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 as well as 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 health care 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

‘Elderspeak’ (i.e. secondary baby talk or infantilization) 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.⁽²⁶⁾ From the observation and interviews, the caregivers indicated that ‘elderspeak’ was the method of communication that has been practised widely in the long-term care facilities, but this method was banned in one of the day care centres involved in our study. It is acknowledged that although “Elderspeak” can be found to be of benefit anecdotally,⁽²⁷⁾ some may find it inappropriate or disrespectful when used during interactions with PWD.⁽²⁸⁾

“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 specialities 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 for them.

“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 during the journey. However, some families were identified as not being supportive in providing the best care for their loved ones, which caused a huge challenge to the caregiver looking after the 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, which 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 family members not only inflicted extra roles for the caregivers but also created more stress and burden to them.

“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

Among the well-recognised non-pharmacological interventions in the management of BPSD around the globe are music therapy, reminiscence therapy, acupuncture, touch therapy and cognitive activities, which have been extensively practised in the local context. Successful interventions require a systematic recognition of potential strategies and the barriers associated with them. The data from this exploratory qualitative study were found to be consistent with the

findings from the literature that 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. The findings have successfully shown that some of their needs were not completely fulfilled and behavioural disturbances manifested as the outcome. Questioning the caregivers uncovered that the main reason for the above issues was due to 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 (2017) stated in their study that environmental consideration and social aspects are required for comprehensive execution of personalised care management, as these elements were 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, the concept of need-driven behaviour (NDB) should be learned by the care providers, in order to recognise the key inducers of NDB (i.e. background condition of the disease and the related factors).⁽³²⁾ Structured methodologies using dementia care mapping (DCM), treatment route for exploring agitation (TREA) and describe, investigate, create, evaluate (DICE) were additionally beneficial in aiding decision making before delivering non-pharmacological interventions. However, these useful methods required standardisation of agreed guidelines nationwide for better management of BPSD as well as increasing the competency of and empowering care providers.⁽³³⁾

Collaborative care in shared decision making was mentioned as one of the successful strategies in managing BPSD in the local setting. This finding was consistent with recommendations by Callahan et al. (2006), that collaborative care should be practised due to the high reliability of strong evidence-based medicine.⁽³⁴⁾ A systematic review also stated that 17% of the failure in delivering non-pharmacological interventions was due to unsupportive family,⁽³⁵⁾

thus, long term education and support by the family members were essential. In this study, the caregivers also complained about lack of support from the family members, which became a huge limitation in incorporating non-pharmacological interventions. Responses from the caregivers indicated that ‘trust issues’ within family members was the major challenge that halts the caregiving flow. These findings were supported by a previous study that reported high rates of burden, social isolation, physical ill-health, and financial hardship as the root of negative attitudes observed within family members.⁽³⁶⁾ This study, however, did not include the perspective of family members in dementia care, thus, similar exploratory research can be performed in future to address it.

In this study, PWD were actively engaged in conversations and 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 the combination of verbal and non-verbal communication as very 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⁾

‘Elderspeak’ is a finding that contributes to the area where existing literature is limited. Most caregivers in nursing homes perpetuated the benefits 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 ‘elderspeak’ calmed the challenging behaviours, increased cooperation in performing tasks,⁽³⁸⁾ provided warmth and increased succourance,⁽²⁷⁾ and sentence comprehension.⁽³⁹⁾ 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, thus, 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 here, and the PWD were of the three main ethnic groups in Malaysia. Additionally, since the 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 were 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 rather 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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