

## **Making sense(s) in dementia: a multisensory and motor-based group activity program**

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## **Abstract**

Lack of engagement in meaningful activities is associated with poor quality of life in dementia thus, the development of these activities has been recommended. This pilot study aimed to develop a multisensory and motor-based group activity program for residents with dementia and assess its impact on residents' behavior.

The program was designed using a multisensory and motor-based approach in 16 45-minute weekly sessions tailored to residents' characteristics. Four residents with advanced dementia participated in the program. The frequency and duration of residents' behavior were assessed using video-recordings. All residents participated in the proposed activities, although they were more participative and communicative in some sessions than in others.

Group activity programs based on MSS and MS can be a promising approach for people with advanced dementia, however further research is needed. This study may serve as reference to the implementation of future programs aiming to increase person-centeredness of the care provided.

**Keywords:** multisensory stimulation, motor stimulation, engagement, activity program

## Introduction

Older people with dementia living in residential care homes may spend the majority of their time engaged in no activity, apart from the usual personal care activities<sup>1-3</sup>. This is more evident in moderate to severe stages of dementia<sup>4,5</sup>. The lack of meaningful activities has been associated with a decrease in residents' functional status, increased behavior problems, social isolation and poor quality of life<sup>3,5</sup>. Activity has therefore been recommended in people with dementia as a mean of retaining human abilities and function<sup>6</sup>, by maintaining their connection with the environment and encouraging social interaction<sup>7,8</sup>. Previous research suggests that the involvement in meaningful activities can have a positive effect on the quality of life of residents with dementia and is related to increased levels of relaxation and enjoyment<sup>2,8</sup>, a lower frequency of behavior problems<sup>8,9</sup>, increased alertness and improved functional ability<sup>3</sup>. It has been recommended that, in the middle to late stages of the disease, the activities should focus on fine- and gross-motor and sensory activities<sup>2,7,10</sup>. Consistent with this recommendation, there are currently two main approaches with promising results in people with moderate to severe dementia: Multisensory Stimulation and Motor Stimulation<sup>11-14</sup>.

The purpose of Multisensory Stimulation (MSS) is to provide appropriate and pleasurable experiences through the stimulation of the senses (olfaction, tact, vision, hearing and taste)<sup>11,15</sup>, without the need for complex intellectual reasoning<sup>16,17</sup>. By stimulating the senses in a format that can be understood by the individual, it is expected that people with dementia will respond appropriately to their surroundings and communicate with others<sup>18</sup>, for example, by giving a smile or thanking to the caregiver<sup>15</sup>. MSS has been found to reduce the frequency of behavior problems and apathy<sup>14,16</sup>, improve communication<sup>7,19</sup> and functional performance<sup>20</sup> and increase residents' attentiveness<sup>12,21</sup>. Motor stimulation (MS) aims to maintain or improve, as long as possible, the remaining physical abilities of people with dementia<sup>12,22</sup>. It is related to movement and exercise and, when tailored to each individual's

abilities, MS can provide people with dementia with an activity in which they can succeed<sup>15</sup>. This approach has been found to improve mobility, balance and cognition, reduce falls and delay the decline of performance in daily activities in residents with dementia<sup>22,23</sup>. By combining these two approaches, it is likely that residents will show more awareness to the environment through the stimulation of senses and more active involvement in the activities planned through the stimulation of mobility and participation.

There are few studies which have combined MSS and MS approaches in structured group activity programs for people with dementia<sup>7,13,24</sup>. Those have reported improvements in strength and flexibility<sup>24</sup>, physical activity, mood<sup>13</sup> and a reduction of agitation<sup>24</sup> after program implementation. However, these studies fell short in offering guidance regarding engagement strategies during the activity programs<sup>25</sup>, hindering their replication. Moreover, to our knowledge, only one study<sup>7</sup> reported the level of residents' engagement during the activity sessions and, therefore, the question of whether people with advanced dementia can actively participate in these programs remains unanswered, as attendance at programs does not guarantee residents' engagement<sup>5</sup>. Hence, it is essential to include direct observation of residents' behavior during activity programs.

This pilot study aimed to: i) develop a multisensory and motor-based activity program designed for institutionalized older people with moderate to severe dementia consisting of structured group-session activities, and; ii) assess residents' behaviors during the program sessions, focused on aspects of engagement. The term *engagement* was previously defined by Cohen-Mansfield and colleagues as "*the act of being occupied or involved with an external stimulus*"<sup>25</sup>. It includes the level of attention to the stimulus and the attitude/action towards it. In this study, it was expected that providing residents with activities appropriate to their cognitive and functional levels and tailored to their interests would result in their active involvement in the proposed activities and facilitate their social engagement.

## **Methods**

### **Setting**

The study was conducted in a traditional care home for older people, in the central region of Portugal. Care homes are defined as a social response developed to provide temporary or permanent accommodation for older people at increased risk of loss independence and/or autonomy<sup>26</sup>, including people with dementia. The manager of the care home was first contacted to assess the willingness of the institution to collaborate in the study, after the description of its purpose and methods. No simultaneous participation in similar studies during the program implementation was ensured. The care home had 53 licensed beds for older people and 21 were occupied by people with a clinical diagnosis of dementia.

### **Participants**

Eligible participants were identified by the physician of the care home. To participate in the study, residents had to meet the following criteria: presenting a clinical diagnosis of moderate to severe dementia according to Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition [DSM-IV]) criteria<sup>27</sup>, having no major psychiatric comorbidities and not being bedridden. Thirteen residents were identified, but two died before informed consent collection. Given the progressive decline that people with dementia experience in their ability to fully understand the context of the research and the implications of their participation<sup>28</sup>, the informed consent was obtained from proxy consent. The researchers contacted legal guardians (all family members), provided them with information about the study and asked to sign the informed consent. Written informed consent was obtained from 7 legal guardians. Four declined due to lack of interest (n=2) or not wishing the resident to be video-recorded (n=2). However, one of the residents died before the study began and his/her information had to be removed from the study. In each program session, the residents were asked to participate to obtain their assent, i.e., their ongoing willingness to participate in the study. Two residents refused to

participate in all sessions and therefore their information was removed from the study.

The sample comprised 4 residents with moderate to severe dementia. Data regarding residents' characteristics were collected at baseline with the aim of describing the sample and adjusting the program accordingly: residents' socio-demographic data, lifetime history and stimulus preference list (e.g., favorite hobbies, music, dishes, etc.) were obtained from family members; residents' global functional ability was measured using the Barthel Index<sup>29</sup>; the level of cognitive impairment was assessed using the Portuguese version of the Cognitive Impairment Test of the Elderly Assessment System (EASYcare)<sup>30</sup>, which has been proved to be a faster and simpler test of cognition with better sensitivity and specificity than Mini-Mental State Examination<sup>31</sup>.

The characteristics of the residents are summarized in Table 1. The assessment of global functional ability revealed that 2 patients were totally dependent in performing activities of daily living, while the other 2 showed moderate levels of dependency. Three residents had a restriction in mobility and were prescribed with walking aids.

[INSERT TABLE 1 HERE]

## **Multisensory and motor-based group activity program**

### *Program design*

The program was designed according to an extensive literature review regarding therapeutic interventions for people with moderate to severe dementia, specifically MSS<sup>7,12,15,17,24,32</sup> and MS<sup>12,13,15,23</sup>. These interventions are based on principles that fit in a person-centered approach, i.e., they need to be adapted to residents' needs, preferences and abilities to enable positive meaningful connections between caregivers and people with advanced dementia<sup>10,33</sup>. Therefore, the program was adjusted to participants' cognitive and functional ability levels and tailored to their interests<sup>5,34</sup>.

The program was planned to be implemented in a small-group format. The number of

participants in these programs should be limited from 4 to 9 people, to avoid the occurrence of challenging behaviors, encourage residents' involvement in the proposed activities and promote social interaction without compromising the individualized approach<sup>3,15</sup>. The program description and implementation are presented in the Results section.

### **Data Collection**

The behaviors of residents with dementia were assessed using video-recordings collected during the sessions. As proposed by Martin and colleagues<sup>33</sup>, the observation of residents' behavior is the best way to recognize when a meaningful connection is occurring and, therefore, the only viable method to assess the well-being of residents with advanced dementia. Video-recordings were chosen instead of direct observation because they enable reviewing the events as often as necessary<sup>35</sup> and provide important information that can be lost during direct observation<sup>36</sup>. In each session, researchers fastened the video-camera to a top of a tripod and turned on just before the session started. The camera was placed in a specific location in the room where it would not interfere with participants' movements and enabled video-recording of all participants, including their faces. A total of 16 video-recordings were collected, one per session.

### **Data Reduction**

The selection of video footage for analysis was defined as: observation time started when the resident appeared on the screen and it ended when the resident completed the gustatory stimulus task. The length of the smallest video-recording was 17 minutes and 53 seconds. Thus, it was pre-established that the other video-recordings would be cut from the starting point to standardize observation time, to allow comparisons between participants and sessions. This methodology has been used previously<sup>12</sup>.

## **Outcome Measures**

Residents' behaviors were studied by analyzing the frequency and duration of a list of behaviors (ethogram). It derived from previous research<sup>12,33,37,38</sup> and preliminary observations of the video-recordings regarding engagement aspects (i.e., level of attention to the stimulus and attitude/action towards it<sup>25</sup>). The list was developed prior to video-recording analyzes and comprised the following categories: engagement in the task, interaction with objects, verbal communication, smiling, laughing, nodding with the head and closed eyes. The behavior categories are described in Table 2. According to Cohen-Mansfield<sup>25</sup>, the first three categories are related to action towards the stimulus, the next three with a positive attitude towards the stimulus and the last with reduced attention to it.

[INSERT TABLE 2 HERE]

## **Data analysis**

### *Analysis of the video-recordings*

Two observers analyzed the video-recordings and independently rated residents' behaviors according to the ethogram using specialized software, Noldus The Observer® XT 10.0 (Noldus International Technology, Wageningen, The Netherlands). Observers were trained to use the software previously to video-recording analyzes. This methodology was used in previous studies with people with dementia to reduce observation bias with good reliability results<sup>12,14</sup>. Frequency and duration of the categories were measured for each resident in all sessions by both observers. Inter-observer reliability analysis was then performed for each behavior category using the recommended methods for conducting reliability studies with continuous data<sup>39</sup>: Intraclass correlation coefficient (ICC)<sup>40</sup> and Bland and Altman method<sup>41</sup>. The ICC equation (2,1) (two-way random effects model)<sup>42</sup> was used.

The ICC values showed excellent to moderate inter-observer reliability for both frequency and

duration of the categories *engagement in the task, interaction with objects, verbal communication and laughing*<sup>40</sup>. Lower ICC values were obtained for duration of *smiling, nodding with the head*, and for frequency and duration of *closed eyes*. These low ICC values may be attributed to the influence of between-subjects variance on the ICC value<sup>39</sup>; in these categories, the between-subjects variance may not be large enough to obtain a high value in ICC. This is one of the main reasons why the inter-observer reliability is recommended to be performed using both methods (ICC and Bland and Altman plots). There was reasonable agreement between observers according to Bland and Altman method with no evidence of systematic bias. Table 3 provides a detailed description of ICC and Bland and Altman values.

[INSERT TABLE 3 HERE]

#### *Residents' attendance and behavior in program sessions*

At the beginning of each session, residents were asked to participate; therefore, residents' attendances as well as reasons for non-attendance were assessed. Descriptive statistics of the behavior categories were calculated for all residents and for each resident independently using PASW Statistics (Predictive Analytics Software) version 18.0 for Windows (SPSS Inc., Chicago, Illinois). Non-parametric multiple comparison Friedman's test was carried out for each behavior category to assess significant differences between sessions. Pearson correlation coefficients ( $r$ ) were also performed to assess relationships between behavior categories. The level of significance considered was 0.05.

## **Results**

### **Multisensory and motor-based activity program**

#### *Program description*

The program consisted of 16 sessions using a multisensory and motor-based approach and it was developed by a multidisciplinary team including 2 physical therapists, 1 gerontologist and

1 educational scientist. The sessions followed a well-defined structure and were organized by a hierarchy of presentation of different stimuli: olfaction, movement (motor activities), touch, vision, hearing and taste. This concept of "*hierarchy*" was previously used by Bowlby<sup>15</sup> and Trudeau<sup>7</sup> and is based on the introduction of stimuli in a sequential manner, from the simplest to the most complex. According to this model of stimulation, olfaction should be the first sense to be stimulated because it is the most primitive sense and the olfactory nerve has projections to the limbic system, the area of the brain responsible for the emotions<sup>43</sup>. Therefore, the stimulation of olfaction can have an arousing and pleasant effect on people with dementia, even in those with some deterioration of the olfactory capacity. Movement should be the second stimulus to be performed because it helps to improve arousal and alertness and is less complex than the following stimuli. Motor function should be stimulated in a simple format without requiring complex motor planning and having a concrete and logical reason for movement (e.g., throwing a ball into a basket). The senses of touch, sight and hearing should be the next to be explored because they are more complex and usually require more time for interpretation. Taste should be stimulated at the end of the session as it is perceived as rewarding and reinforces socialization.

Each session was designed based on a specific theme consistent with residents' preferences and lifetime history. The themes were also chosen in accordance with the season or date in which they would be implemented (e.g., Christmas or Valentine's Day), to offer temporal orientation to participants. The list of themes is presented in Table 4.

[INSERT TABLE 4 HERE]

For each stimulus, a structured task or sensory cue regarding the theme of the session was planned to encourage residents' involvement, following the hierarchy of stimulation mentioned above. Although a single object may provide different types of stimulation (e.g., a pine can provide olfactory, visual and tactile stimulation), emphasis was given to only one sense at a time. The materials selected for providing stimulation were simple, inexpensive and

available in most care homes. An example of a session is described in Table 5.

[INSERT TABLE 5 HERE]

The sessions were planned to last 45 minutes each, which is consistent with previous recommendations<sup>15</sup>. Estimated time frames of approximately 10 minutes for each stimulation cue were set to guide the facilitators (i.e., the professionals who implemented the program sessions). However, these time frames could be extended or shortened depending on participants' responses. Additionally, if a person had a limitation in one sense, the other senses were stimulated to compensate for that one.

During the presentation of stimuli, facilitators provided participants with simple verbal prompts to help stimulating their communication, such as *"What is your favorite color?"*, *"Do you like this fragrance?"* or *"Do you like touching the sand?"*. Because communication is defined as the core of all effective interventions in dementia<sup>44</sup>, a number of recommendations were followed by the facilitators to effectively communicate with the participants during the sessions:

- The facilitator was located close to the resident and called the person by his/her name;
- The facilitator spoke slowly and clearly, using simple and short sentences. When repeating a statement, the same words were used;
- Verbal prompts were asked one at a time, giving time for the resident to respond;
- The facilitator made eye contact when talking to the resident and reinforced verbal cues with visual ones whenever possible. In addition, touch was used to communicate with the residents, although with caution to avoid the occurrence of challenging behaviors;
- Gestures and facial expressions were also used with appropriate verbal cues.

The provision of motor stimulation followed specific strategies and recommendations about the varying levels of assistance offered to participants. This ensured that all residents could participate actively regardless of his/her physical status, giving him/her the best chance to be successful. Facilitators planned in advance what tasks each person could perform and adapted

them according to the following recommendations:

- The person was properly positioned to facilitate the participation in the task;
- Tasks were broken in small steps and simple instructions were given, step-by-step;
- The facilitator demonstrated how to perform the task and then asked the person to do it, using gestures to assist its completion;
- If the person needed assistance, the facilitator helped the starting of the movement or gave physical guidance;
- Careful was taken to avoid rushing the person during the task;
- Periods of rest during the task were given if the person felt tired;
- The person was encouraged and praised after task completion.

#### *Program implementation*

The implementation period lasted 4 months. Sessions were carried out on a weekly basis on the same day of the week, in a room of the care home. The room was quiet and comfortable with proper lightening to ensure patients' participation in activities, but without extraneous stimuli (e.g., TV, radio) and distant from the passing zones to prevent distractions or interruptions. All sessions were facilitated by a physical therapist and a gerontologist, with the support of the activity organizer of the care home who was aware of program specificities. Sessions were carried out between 14:30 and 15:30pm, as these were the times when residents were frequently unoccupied.

#### **Residents' attendance and behavior in program sessions**

Only one resident (Resident 2) attended all sessions (Figure 1). Resident 1 did not attend 3 sessions, Resident 3 missed 1 session and Resident 4 missed 6 sessions. Reasons given included: health-related reasons and hospitalization, family-related reasons, lack of interest to

participate and no reason given.

Table 6 shows the mean frequency and duration of the categories for all residents and for each resident individually. There were no statistically significant differences between the thematic sessions for both indicators of the behavior categories ( $p>0.05$ ) when considering the whole sample. Overall, residents engaged in the proposed tasks for more than five minutes (95% CI, 4.61-6.97), communicated verbally about 34 times (95% CI, 27.21-42.39) and interacted with objects with a mean frequency of 2.15 times during the sessions (95% CI, 1.20-3.10), except for Resident 4 who did not present this behavior.

[INSERT TABLE 6 HERE]

Residents 1 and 2 were the most participative and responsive in the program sessions, presenting higher values in the mean frequency and duration of *engagement in the task*, *interaction with objects*, *verbal communication* and *laughing*, when compared to the other residents (Table 6). In 5 of the attended sessions, these residents spent half or more of the observed time (17 minutes and 53 seconds) engaged in the planned tasks (Figure 1). Furthermore, they were engaged in the tasks for more than 84% of the time in 1 session (*Coffee and table games*); Resident 2 also engaged approximately 88% of the time in other session (*Arts*).

[INSERT FIGURE 1 HERE]

Resident 3 also showed high levels of engagement in the proposed tasks, being engaged more than 1/3 of the total amount of time in 8 of the 15 attended sessions. Lower levels of participation in the sessions were observed for Resident 4. In fact, he did not present some of the positive behaviors observed in other residents (*interaction with objects*, *smiling*, *laughing* and *nodding with the head*), although he did engage and verbally communicate in some sessions.

When assessing correlations between behavior categories, statistically significant results were found. It was possible to observe an inverse correlation between the duration (D) and

frequency (F) of *engagement in the task* and *closed eyes* ( $r=-0.34$ ,  $p=0.012$  (D);  $r=-0.35$ ,  $p=0.008$  (F)). The frequency of *engagement in the task* was positively correlated with the frequency of *smiling* ( $r=0.44$ ,  $p=0.001$  (F)) and *laughing* ( $r=0.39$ ,  $p=0.004$  (F)). A relationship was also found between *verbal communication* and the categories *engagement in the task* ( $r=0.33$ ,  $p=0.014$  (D);  $r=0.52$ ,  $p=0.000$  (F)), *interaction with the objects* ( $r=0.37$ ,  $p=0.005$  (F)), *smiling* ( $r=0.49$ ,  $p=0.000$  (D);  $r=0.51$ ,  $p=0.000$  (F)), *laughing* ( $r=0.32$ ,  $p=0.020$  (D);  $r=0.60$ ,  $p=0.000$  (F)) and *nodding with the head* ( $r=0.39$ ,  $p=0.003$  (F)), suggesting that residents who talked more also presented more positive non-verbal communication behaviors and were more participative in the sessions. The duration of *laughing* was positively related to the same indicator of *interaction with the objects* ( $r=0.29$ ;  $p=0.036$  (D)).

### Discussion

This pilot study developed a multisensory and motor-based group activity program tailored to cognitive and functional abilities, preferences and lifetime history of residents with advanced dementia in care homes. This was needed as the literature has emphasizing the importance of developing meaningful and suitable activities to increase engagement in this population<sup>8,13,17</sup>, especially in advanced stages, for which the activities are either not available or fail to match their skill levels<sup>45,46</sup>. There is relatively little research exploring the impact of the implementation of structured activity programs in residents' behavior and the few published studies failed to fully characterize the intervention<sup>47</sup>, making it difficult to replicate and/or compare different studies. This study tried to overcome this gap in the literature by developing and presenting a detailed group activity program for people with advanced dementia, including the rationale that formed the basis for the program design and information about the strategies used to interact with the residents (communication strategies and assistance). As attendance at activity programs does not guarantee residents' involvement<sup>5</sup>, this study also assessed the immediate effects of the program on the behavior of residents with dementia. It

was expected that providing residents with activities appropriate to their cognitive and functional levels and tailored to their past experience and preferences would result in their active involvement and facilitate social engagement. The results were in agreement with this hypothesis, thus supporting the belief that residents with advanced dementia can effectively participate in the planned activities. Residents appeared to be more alert and responsive to the proposed tasks and demonstrated positive behaviors (e.g., engagement in tasks, verbal communication and laughing) while participating in the weekly sessions. This is an encouraging finding, given that most individuals with dementia have difficulty with attention and often lack the internal resources needed to initiate, maintain or complete an activity<sup>7,48</sup>. Further research is needed to investigate the extent of these findings. The use of MSS and MS approaches may have facilitated residents' engagement and enabled them to successfully participate in the activities, as reported by previous studies using these approaches in other contexts<sup>12,14</sup>. The communication strategies and assistance provided during the sessions may also have facilitated residents' involvement. It is not possible to determine which factor influenced the most residents' behavior; however, these strategies are a key-element in all activity approaches and should not be provided separately<sup>44</sup>.

Overall, residents seem to enjoy most of the attended sessions, although they evidenced more positive behaviors in some sessions rather than in others. These results may be explained by two main factors previously identified in the literature: i) factors related to residents' characteristics, such as their level of function and cognitive impairment<sup>5,8,25</sup>; and/or ii) a combination between the context of past experiences, personal interests and preferences and cultural expectations<sup>2,5,49</sup>. Residents' characteristics may be a barrier to their participation in activities depending on their cognitive and functional levels, which are the main predictors of the variance in engagement as found by Kolanowski and coworkers<sup>5</sup>. A recent guideline developed to support people with dementia and their caregivers<sup>44</sup> highlighted the need of considering the right level of stimulation and challenge for the individual when exploring

appropriate activities. The present study attempted to overcome participants' deficits by designing the program according to their cognitive and functional status and planning the tasks in advance to adapt them accordingly. However, in people with moderate to severe stages of dementia, the function is often highly compromised<sup>15</sup> and may act as a "*limiting effect*" in their participation<sup>5</sup>. Though, it should not be assumed that the person does not retain abilities to perform an activity and, therefore, creative ways need to be explored to maximize the use of each individual's remaining abilities<sup>44</sup>.

The fact that residents participated more actively in specific sessions and less in others may be attributable to their personal preferences and lifetime history. Previous literature has emphasized that the combination between the context of past experiences, personal interests and cultural expectations may play a role in individuals' motivation to participate in activities<sup>2,49,50</sup>. Therefore, a comprehensive assessment of residents' physical, mental and social dimensions<sup>2,5,6,50</sup> is fundamental in the development of these programs<sup>51</sup>. Although the present program was designed considering these dimensions, sessions were performed in a group-format which made the selection of session themes more challenging as residents' preferences were not always consensual. Nevertheless, small-group activities are essential to promote an enriched social environment with opportunities for people with dementia to feel valued and included<sup>10</sup>, reducing the risk of social isolation. Therefore, future research should focus on the development of meaningful activities for people with dementia in a small-group format, to improve their active involvement in activities while promoting social engagement.

Recent guidelines recommend that stimulation interventions should be offered to people with dementia on a regular basis (e.g., daily or weekly)<sup>47</sup>. Though, in residential care homes, it is well recognized that organizational issues such as lack of staff and the prioritization of physical needs over psychosocial ones may be a barrier to implement these activities as part of fundamental care<sup>2,33</sup>. Therefore, important shifts in dementia care need to be conducted in the next decades to achieve a high quality of care. Specifically, the development of meaningful and

structured group activities for people with advanced dementia should become a priority within their care practices in order to promote residents' comfort, quality of life and human dignity.

### **Limitations and future research**

This study adds knowledge to the literature on structured group activity programs for people with advanced stages of dementia in the context of residential care by showing that residents can effectively participate in the program sessions. However, the sample was small and, thus, the program should be replicated with a larger sample to investigate whether similar results are obtained. The program was implemented in only one care home because the main focus of this pilot study was to assess the adequacy of the intervention to the target population. This is required before the implementation of the program in a larger study<sup>52</sup>. Therefore, as the results look promising, the inclusion of more care homes should be addressed in future studies.

### **Conclusion**

The findings suggest that structured group activity programs based on MSS and MS approaches can be a promising approach for people with advanced dementia. Given the well-documented lack of residents' engagement observed in most care homes and its potential to increase excess disability and behavior problems, similar interventions are urgently needed to promote residents' comfort, quality of life and human dignity. The present program may serve as reference to the development of future programs exploring residents' engagement aiming to increase person-centeredness of the care provided.

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## References

1. Kuhn D, Kasayka RE, Lechner C. Behavioral observations and quality of life among persons with dementia in 10 assisted living facilities. *Am J Alzheimers Dis Other Demen.* 2002;17(5):291-298.
2. Harmer BJ, Orrell M. What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging Ment Health.* 2008;12(5):548-558.
3. Cohen-Mansfield J, Thein K, Dakheel-Ali M, Marx MS. Engaging nursing home residents with dementia in activities: The effects of modeling, presentation order, time of day, and setting characteristics. *Aging Ment Health.* 2010;14(4):471-480.
4. Clare L, Whitaker R, Quinn C, et al. AwareCare: Development and validation of an observational measure of awareness in people with severe dementia. *Neuropsychol Rehabil.* 2012;22(1):113-133.
5. Kolanowski A, Buettner L, Litaker M, Yu F. Factors that relate to activity engagement in nursing home residents. *Am J Alzheimers Dis Other Demen.* 2006;21(1):15-22.
6. Thelander VB, Wahlin T-BR, Olofsson L, Heikkilä K, Sonde L. Gardening activities for nursing home residents with dementia. *Adv Physiother.* 2008;10(1):53-56.
7. Trudeau SA. Bright Eyes: A Structured Sensory-Stimulation Intervention. In: Volicer L, Bloom-Charette L, eds. *Enhancing the quality of life in advanced dementia.* Philadelphia: Taylor & Francis; 1999:93-105.
8. Riley P, Alm N, Newell A. An interactive tool to promote musical creativity in people with dementia. *Comput Human Behav.* 2009;25(3):599-608.
9. Buettner LL. Simple Pleasures: A multilevel sensorimotor intervention for nursing home residents with dementia. *Am J Alzheimers Dis Other Demen.* 1999;14(1):41-52.
10. Brooker D. *Person-Centred Dementia Care: Making Services Better* London: Jessica Kingsley Publishers; 2007.

11. Baker R, Holloway J, Holtkamp CCM, et al. Effects of multi-sensory stimulation for people with dementia. *J Adv Nurs*. 2003;43(5):465-477.
12. Cruz J, Marques A, Barbosa AL, Figueiredo D, Sousa L. Effects of a Motor and Multisensory-Based Approach on Residents With Moderate-to-Severe Dementia. *Am J Alzheimers Dis Other Demen*. 2011;26(4):282-289.
13. Heyn P. The effect of a multisensory exercise program on engagement, behavior, and selected physiological indexes in persons with dementia. *Am J Alzheimers Dis Other Demen*. 2003;18(4):247-251.
14. van Weert JCM, van Dulmen AM, Spreeuwenberg PMM, Ribbe MW, Bensing JM. Effects of snoezelen, integrated in 24 h dementia care, on nurse-patient communication during morning care. *Patient Educ Couns*. 2005;58(3):312-326.
15. Bowlby C. *Therapeutic Activities With Persons Disabled by Alzheimer's Disease and Related Disorders*. Shoal Creek Boulevard, Texas: Pro-Ed Inc.; 1992.
16. Verkaik R, Weert JCMv, Francke AL. The effects of psychosocial methods on depressed, aggressive and apathetic behaviors of people with dementia: a systematic review. *Int J Geriatr Psychiatry*. 2005;20(4):301-314.
17. Vozzella S. Sensory Stimulation in Dementia Care: Why It Is Important and How to Implement It. *Top Geriatr Rehabil*. 2007;23(2):102-113.
18. Baillon S, van Diepen E, Prettyman R. Multi-sensory therapy in psychiatric care. *Adv Psychiatr Treat*. 2002;8(6):444-450.
19. Hope KW, Easby R, Waterman H. 'Finding the person the disease has' - The case for multisensory environments. *J Psychiatr Ment Health Nurs*. 2004;11(5):554-561.
20. Collier L, McPherson K, Ellis-Hill C, Staal J, Bucks R. Multisensory Stimulation to Improve Functional Performance in Moderate to Severe Dementia—Interim Results. *Am J Alzheimers Dis Other Demen*. 2010;25(8):698-703.
21. Van Weert JCM, Janssen BM, Van Dulmen AM, Spreeuwenberg PMM, Bensing JM, Ribbe

- MW. Nursing assistants' behaviour during morning care: effects of the implementation of snoezelen, integrated in 24-hour dementia care. *J Adv Nurs*. 2006;53(6):656-668.
- 22.Christofoletti G, Oliani MM, Gobbi S, Stella F. Effects of Motor Intervention in Elderly Patients With Dementia: An Analysis of Randomized Controlled Trials. *Top Geriatr Rehabil*. 2007;23(2):149-154
- 23.Rolland Y, Pillard F, Klapouszczak A, et al. Exercise Program for Nursing Home Residents with Alzheimer's Disease: A 1-Year Randomized, Controlled Trial. *J Am Geriatr Soc*. 2007;55(2):158-165.
- 24.Buettner LL, Lundegren H, Lago D, Farrell P, Smith R. Therapeutic recreation as an intervention for persons with dementia and agitation: An efficacy study. *Am J Alzheimers Dis Other Demen*. 1996;11(5):4-12.
- 25.Cohen-Mansfield J, Dakheel-Ali M, Marx MS. Engagement in persons with dementia: the concept and its measurement. *Am J Geriatr Psychiatry*. 2009;17(4):299–307.
- 26.Bonfim CdJ, Garrido MM, Saraiva ME, Veiga SM. *Lar para Idosos - Condições de implantação, localização, instalação e funcionamento*. Lisboa: Direcção-Geral da Acção Social; 1996.
- 27.American Psychiatric Association. *DSM-IV-TR - Manual de Diagnóstico e Estatística das Perturbações Mentais*. 4ª ed. Lisboa: Climepsi Editores; 2000.
- 28.Slaughter S, Cole D, Jennings E, Reimer MA. Consent and Assent to Participate in Research from People with Dementia. *Nurs Ethics*. 2007;14(1):27-40.
- 29.Mahoney F, Barthel D. Functional evaluation: the Barthel Index. *Md State Med J*. 1965;14:56-61.
- 30.Figueiredo D, Sousa L. [EASYcare: an instrument for assessing the quality of life and well being of the elderly]. EASYcare: um instrumento de avaliação da qualidade de vida e bem estar do idoso. *Ver Port Med Geriatr*. 2001;130:41-47.
- 31.Brooke P, Bullock R. Validation of a 6 item cognitive impairment test with a view to primary

- care usage. *Int J Geriatr Psychiatry*. 1999;14(11):936-940.
32. Fowler S. *Sensory stimulation: sensory-focused activities for people with physical and multiple disabilities*. London: Jessica Kingsley Publishers; 2007.
33. Martin GA, Mockbee D, Alonzo T, Deyo J, Dougherty J, Horton A. Activity Programming. In: Martin GA, Sabbagh MN, eds. *Palliative care for advanced Alzheimer's and dementia: guidelines and standards for evidence-based care*. New York: Springer Publishing Company; 2011:153-169.
34. Cohen-Mansfield J, Marx MS, Thein K, Dakheel-Ali M. The impact of past and present preferences on stimulus engagement in nursing home residents with dementia. *Aging Ment Health*. 2010;14(1):67-73.
35. Hansebo G, Kihlgren M. Carers' interactions with patients suffering from severe dementia: a difficult balance to facilitate mutual togetherness. *J Clin Nurs*. 2002;11(2):225-236.
36. Haidet KK, Tate J, Divirgilio-Thomas D, Kolanowski A, Happ MB. Methods to improve reliability of video-recorded behavioral data. *Res Nurs Health*. 2009;32(4):465-474.
37. Altus DE, Engelman KK, Mathews RM. Finding a practical method to increase engagement of residents on a dementia care unit. *Am J Alzheimers Dis Other Demen*. 2002;17(4):245-248.
38. Perrin T. The Positive Response Schedule for Severe Dementia. *Aging Ment Health*. 1997;1(2):184 - 191.
39. Rankin G, Stokes M. Reliability of assessment tools in rehabilitation: an illustration of appropriate statistical analyses. *Clin Rehabil*. 1998;12(3):187-199.
40. Fleiss J. Reliability of measurements. In: Fleiss J, ed. *The design and analysis of clinical experiments*. 1 ed. New York: John Wiley & Sons; 1986.
41. Bland MJ, Altman DG. Statistical Methods for Assessing Agreement between Two Methods of Clinical Measurement. *Lancet*. 1986;327(8476):307-310.
42. Shrout PE, Fleiss JL. Intraclass correlations: Uses in assessing rater reliability. *Psychol Bull*.

1979;86(2):420-428.

43. Widmaier EP, Raff H, Strang KT. *Vander, Sherman, Luciano's Human Physiology: The Mechanisms of Body Function* 9ed. USA: Mcgraw-Hill; 2003.
44. National Collaborating Centre for Mental Health (UK). *Dementia: A NICE–SCIE Guideline on supporting people with dementia and their carers in health and social care - National Clinical Guidelines N. 42*. Leicester: British Psychological Society; 2007.
45. Collier L. Planning and implementing sensory interventions. In: Pool J, ed. *The Pool Activity Level (PAL) Instrument for Occupational Profiling: a practical resource for carers of people with cognitive impairment*. 4 ed. London: Jessica Kingsley Publishers; 2012:140-153.
46. Kovach CR, Magliocco JS. Late-stage dementia and participation in therapeutic activities. *Appl Nurs Res*. 1998;11(4):167-173.
47. American Psychiatric Association A. *Practice Guideline For The Treatment of Patients With Alzheimer's Disease and Other Dementias*. Arlington (VA): American Psychiatric Association (APA); 2007.
48. Kolanowski A, Litaker M. Social Interaction, Premorbid Personality, and Agitation in Nursing Home Residents With Dementia. *Arch Psychiatr Nurs*. 2006;20(1):12-20.
49. LeBlanc LA, Cherup SM, Feliciano L, Sidener TM. Using Choice-Making Opportunities to Increase Activity Engagement in Individuals With Dementia. *Am J Alzheimers Dis Other Demen*. 2006;21(5):318-325.
50. Edvardsson D, Fetherstonhaugh D, Nay R. Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *J Clin Nurs*. 2010;19(17-18):2611-2618.
51. Dobbs D, Munn J, Zimmerman S, et al. Characteristics Associated With Lower Activity Involvement in Long-Term Care Residents With Dementia. *Gerontologist*. 2005;45(suppl 1):81-86.
52. Conn VS, Algase DL, Rawl SM, Zerwic JJ, Wyman JF. Publishing Pilot Intervention Work.

*West J Nurs Res.* 2010;32(8):994-1010.

53. Shah S, Vanclay F, Cooper B. Improving the sensitivity of the Barthel Index for stroke rehabilitation. *J Clin Epidemiol.* 1989;42:703-709.

**Table 1** – Characteristics of the residents with dementia.

Residents	Age	Gender	Clinical diagnosis	EASYcare		
				Cognitive Impairment Test <sup>(1)</sup>	Barthel Index <sup>(2)</sup>	Use of walking aid
1	85	Female	Severe	25	75	No
2	92	Female	Moderate	12	90	Walking stick
3	74	Male	Moderate	25	10	Wheelchair
4	75	Male	Moderate	16	0	Wheelchair

<sup>(1)</sup>Scores from 0 to 28 points. A score  $\geq 11$  indicates moderate to severe cognitive impairment.

<sup>(2)</sup>Scores from 0 to 100 points. Cutoff scores of the Barthel Index according to Shah and colleagues<sup>53</sup>: 0-20 total dependency; 61-90 moderate dependency; 91-99 slight dependency.

**Table 2** – Behavior categories of the ethogram.

<b>Category</b>	<b>Description of the category</b>
Engagement in the task	The resident moves the body or a body part in order to perform a task, or a part of it, related with a specific task of the session (e.g., tossing the ball to a group-leader or putting land into the jar). The task has a specific and pre-defined purpose and its completion can be accomplished with the assistance of a group-leader, for example through verbal commands or physical guidance.
Interaction with objects	The resident moves the body or a body part in the direction of an object, reaching it. He/she can explore the object or not. This action is voluntary, that is, the group-leaders do not give any instructions to the resident to reach the object (for example, pick up the sunglasses and try them on).
Verbal communication	The resident articulates words or sentences with meaning, voluntarily and purposely, in order to communicate with other person (a group-leader, a staff element or another resident). Verbal aggression is excluded.
Smiling	The resident produces a facial expression characterized by an upward curving of the corners of the mouth indicating pleasure or amusement, which is directed to a person or an object.
Laughing	The resident smiles and produces a sound commonly associated with the act of laughing.
Nodding with the head	The resident nods with his/her head in an affirmative response to an auditory and/or visual stimulus, directed by another person (a group-leader, a staff element or another resident).
Closed eyes	The resident closes his/her eyes and keeps them closed for more than one second.

**Table 3 – Results of the inter-observer reliability analysis.**

		ICC	ICC 95% CI	$\bar{d}$	$SD_{\text{differences}}$	SE of $\bar{d}$	95% limits of agreement
Engagement in the task	F	0.84	0.75; 0.90	0.38	5.87	0.75	-11.36; 12.11
	D	0.90	0.82; 0.95	-44.47	110.98	15.10	-266.44; 177.49
Interaction with objects	F	0.73	0.58; 0.83	0.07	2.98	0.38	-5.89; 6.02
	D	0.48	0.25; 0.66	-0.40	71.12	9.68	-142.64; 141.85
Verbal communication	F	0.91	0.84; 0.95	-4.70	13.19	1.80	-31.08; 21.68
	D	0.45	0.21; 0.64	-10.99	98.04	13.34	-207.07; 185.07
Closed eyes	F	0.38	0.14; 0.57	0.24	3.82	0.52	-7.39; 7.87
	D	0.40	0.15; 0.60	-12.23	98.88	13.46	-209.99; 185.53
Smiling	F	0.51	0.30; 0.68	-0.11	1.46	0.20	-3.04; 2.81
	D	0.37	0.11; 0.58	-0.38	4.26	0.58	-8.90; 8.15
Laughing	F	0.86	0.78; 0.91	0.32	1.32	0.18	-2.32; 2.96
	D	0.62	0.42; 0.76	0.93	3.07	0.42	-5.20; 7.06
Nodding with the head	F	0.70	0.54; 0.81	-0.72	2.12	0.29	-4.97; 3.52
	D	0.33	0.07; 0.55	0.42	5.95	0.81	-11.48; 12.33

F – Frequency (number of times the behavior was present); D – Duration (total time the behavior was present, in seconds); ICC – Intraclass correlation coefficient; ICC 95% CI – ICC 95% confidence intervals;  $\bar{d}$  – mean of the differences between results obtained from the 2 observers;  $SD_{\text{differences}}$  – standard deviation of the differences; SE of  $\bar{d}$  – Standard error of the mean difference ( $SE=SD_{\text{differences}}/\sqrt{n}$ ); 95% limits of agreement using the Bland and Altman method ( $\bar{d}\pm 1.96*SD_{\text{differences}}$ )

**Table 4 – Themes of the sessions.**

<b>Themes</b>	
1. Grape harvest	9. New Year
2. Celebration – roasted chestnuts <sup>(1)</sup>	10. Relaxation
3. Gardening	11. Remembering Aveiro <sup>(2)</sup>
4. Coffee and table games	12. Old traditional festivities
5. Music	13. Sports
6. Arts	14. School time
7. Beach	15. Valentine’s day
8. Christmas	16. Self-care

<sup>(1)</sup>This is a traditional festivity of Portugal named “*Magusto*” which occurs on November 11<sup>th</sup>.

People celebrate it eating roasted Portuguese chestnuts.

<sup>(2)</sup>Aveiro is a city in the central region of Portugal, in which the program took place.

**Table 5** – Description of one session with the theme *Beach*.

<b>Stimulation cue/task</b>	<b>Description</b>
<b>Olfaction</b>	Olfactory stimulation is introduced through a sea-scented air freshener.
<b>Movement</b>	<p>A beach ball game is planned to stimulate movement. The game consists of throwing the ball and receiving it (similar to the usual ball games). The ball can be thrown to the facilitator or other participants. Facilitators can give simple step-by-step instructions, either verbal (“Throw the ball forward!”, “Send the ball to me!”) or non-verbal (making gestures to explain what is intended with the game or exemplifying the activity).</p> <p>People who are able to walk independently can be asked to walk barefoot on sand previously placed on a floor area of the room (in a protective plastic to prevent contamination).</p>
<b>Touch</b>	People are encouraged to touch the sand (dry and wet), water or other beach-related objects (e.g., sea shells, beach towels, sunglasses).
<b>Vision</b>	The vision is stimulated by presenting images related to the beach, such as the beach the participants used to go, images of fishes, shells and colored sunshades. Images must be clear and unambiguous, with bright colors and high contrast, and can be presented either on paper or through an image projector.
<b>Hearing</b>	The hearing can be stimulated simultaneously with the vision by playing the sound of ocean waves or seagulls.
<b>Taste</b>	The taste can be stimulated by offering ice cream.

**Table 6 – Residents’ behavior during participation in the Multisensory and motor-based activity program.**

		Resident 1	Resident 2	Resident 3	Resident 4	All Residents	
		mean±SD	mean±SD	mean±SD	mean±SD	mean±SD	95% CI
Engagement in the task	F	16.38 ± 12.32	16.78 ± 6.24	14.87 ± 6.11	1.10 ± 1.41	11.73 ± 9.90	9.20; 14.26
	D	6.90 ± 4.75	8.28 ± 3.65	5.82 ± 2.83	0.34 ± 0.57	5.79 ± 4.34	4.61; 6.97
Interaction with objects	F	5.12 ± 6.36	2.72 ± 2.71	1.40 ± 1.29	0	2.15 ± 3.71	1.20; 3.10
	D	1.25 ± 1.54	0.76 ± 0.88	0.38 ± 0.40	0	0.63 ± 1.00	0.36; 0.90
Verbal communication	F	56.08 ± 27.11	63.00 ± 17.73	17.60 ± 10.29	12.20 ± 10.74	34.08 ± 29.63	27.21; 42.39
	D	1.99 ± 1.38	2.54 ± 0.92	0.76 ± 0.60	1.21 ± 1.66	1.67 ± 1.33	1.30; 2.03
Closed eyes	F	0.23 ± 0.56	0	0	4.15 ± 5.57	0.73 ± 2.66	0.05; 1.41
	D	0.01 ± 0.03	0	0	1.73 ± 2.57	0.10 ± 0.07	0.08; 0.12
Smiling	F	1.54 ± 2.11	0.47 ± 0.85	0.17 ± 0.52	0	0.49 ± 1.21	0.18; 0.80
	D	0.05 ± 0.09	0.01 ± 0.03	0.01 ± 0.04	0	0.02 ± 0.05	0.01; 0.03
Laughing	F	1.62 ± 2.39	2.87 ± 3.29	0.10 ± 0.28	0	1.12 ± 2.31	0.53; 1.71
	D	0.03 ± 0.06	0.06 ± 0.07	0.01 ± 0.02	0	0.03 ± 0.05	0.01; 0.04
Nodding with the head	F	1.38 ± 1.26	3.50 ± 3.39	1.77 ± 2.29	0	1.65 ± 2.47	1.01; 2.28
	D	0.03 ± 0.03	0.05 ± 0.07	0.05 ± 0.11	0	0.04 ± 0.07	0.02; 0.05

F – Frequency (number of times the behavior was present); D – Duration (total time the behavior was present, in minutes); SD – Standard Deviation; 95% CI - 95% confidence intervals for the mean of the behaviors presented by all residents.

**Figure 1** – Duration of the category *engagement in the task* for each resident in each session.

