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TITLE PAGE

Full Title: Engagement of a Person with Dementia Scale: Establishing Content Validity and Psychometric Properties

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IMPACT STATEMENT

Engaging a person with dementia in meaningful activity is important. The *Engagement of a Person with Dementia Scale* (EPWDS) assesses the behavioural and emotional expressions and responses of engagement by people with dementia when partaking in a psychosocial activity in five areas: affective, visual, verbal, behavioural, and social engagement. Validation of the concept and content of the EPWDS by a Delphi expert panel, as well as the establishment of its psychometrics properties, ensures the EPWDS is a valid and reliable resource for researchers and clinicians to assess engagement, and to enhance opportunities for meaningful activities in people with dementia.

ABSTRACT

Aim: To develop and psychometrically test the Engagement of a Person with Dementia Scale.

Background: It is important to study engagement in people with dementia when exploring the effectiveness of psychosocial interventions that can promote meaningful activity, stimulation and wellbeing, through an increase in positive emotions and an improvement in quality of life. The Engagement of a Person with Dementia Scale was developed based on current literature and previous research work on a video coding tool to ascertain the effect of psychosocial interventions on engagement in people with dementia.

Design/Method: Using the Delphi technique, the content validity of the scale was evaluated by 15 dementia experts and formal/informal dementia carers. Psychometric properties of the scale were evaluated using 131 videos of people with dementia presented with PARO – a therapeutic, interactive, robotic seal – in long-term aged care facilities.

Results: A 10-item scale was established following the rewording, combining and elimination of prospective items, with revisions made to the instructions for using and scoring the scale. An overall consensus with agreement for the scale was established among the panel of experts. The scale demonstrated robust internal consistency, inter-rater and test-retest reliability and convergent and discriminant validity.

Conclusion: This study successfully developed the *Engagement of a Person with Dementia Scale*, with established content validity and psychometric properties. The scale assesses the behavioural and emotional expressions and responses of engagement by people with dementia when partaking in a psychosocial activity in five areas: affective, visual, verbal, behavioural and social engagement.

KEYWORDS: instrument development, dementia, Delphi technique, psychometric testing, nurses, nursing

SUMMARY STATEMENT

Why is this research needed?

- Engaging a person with dementia in meaningful activity is important, as it can improve quality of life and reduce behavioural and psychological symptoms of dementia.
- Existing assessment tools on engagement are either not specifically designed for people with dementia who have reduced intensity of emotional response or have a limited focus on social interaction.
- A fresh means to manage the appraisal of engagement in people with dementia, that takes into consideration both social interaction and activity participation, is necessary.

What are the key findings?

- Content validity of the Engagement of a Person with Dementia Scale is supported by panel experts in the Delphi study, with an overall agreement of 81.4%.
- Robust psychometrics in terms of internal consistency, inter-rater and test-retest reliability and convergent and discriminant validity were established for the *Engagement of a Person with Dementia Scale*.
- *Engagement of a Person with Dementia Scale* is a valid and reliable resource for researchers and clinicians to assess engagement to enhance opportunities for meaningful activities in people with dementia.

How should the findings be used to influence policy/practice/research/education?

- The Engagement of a Person with Dementia Scale can help researchers to examine and recommend meaningful activities for people with dementia.
- The Engagement of a Person with Dementia Scale can provide nursing staff with a tool to assess engagement to enhance opportunities for meaningful activities in people with dementia.

1 INTRODUCTION

Dementia, of which Alzheimer's disease is the most common type, is a growing international epidemic. Worldwide, 46.8 million people have dementia and this figure is expected to double every 20 years, reaching 131.5 million in 2050 (World Health Organization & Alzheimer's Disease International, 2015). Dementia results in a progressive deterioration of mental and physical functioning and a gradual decline in the ability to communicate. For people with dementia living in long-term aged care, the majority of their time is often spent alone, doing little and with little opportunity for engagement and, in particular, in meaningful activity (von Kutzleben et al., 2012, Moyle et al., 2011b, Roos and Malan, 2012). Residing in an environment that may limit social connection can lead to feelings of loneliness (Roos & Malan, 2012). Consequently, feeling lonely and being socially isolated (Moyle et al., 2011a), as well as cognitive decline, can increase alongside limited stimulation (Ray and Davidson, 2014). In addition, limited social connection with family and others can result in unmet social needs and lead to an increase in behavioural and psychological symptoms of dementia, for example, agitation, aggression, depression and apathy (Scherder et al., 2010, Mitchell et al., 2016). Therefore, the determination of meaningful and stimulating activities is imperative in the care of people with dementia.

The study of engagement is important to determine meaningful activity for people with dementia. The state of engagement is defined as the state in which individuals express their entire self – physically, cognitively and emotionally (Kahn, 1990). Cohen-Mansfield and colleagues (2011) defined engagement in dementia as *'the act of being occupied or involved with an external stimulus'*. Engagement is considered as either social interaction or activity participation, assessed through behavioural observations.

Engagement supports wellbeing by encouraging individuals to feel good about themselves, brings meaning to their lives, helps them feel a sense of belonging and provides opportunities for using their skills. The benefits of engagement in meaningful activity do not change with a diagnosis of dementia (Alzheimer's Australia Victoria, 2016). Generally, engagement has been loosely examined through self-report

assessment of an individual's interest and involvement toward activity that leads to positive benefits. However, it is challenging and difficult to measure reliable and valid engagement in people with dementia. Conventional self-report methods for engagement can be challenging for people with dementia, as they may struggle to remember activities in which they participate, recall how they felt during activities, as well as report accurately on their experiences. Largely, research to date has highlighted the importance of studying engagement in dementia to determine the effectiveness of psychosocial interventions that can promote meaningful activity, stimulation and wellbeing through an increase in positive affect (Schreiner et al., 2005, van der Ploeg et al., 2013, Moyle et al., 2013, Materne et al., 2014) and an improvement in activities of daily living, as well as quality of life (Gitlin et al., 2009, van der Ploeg et al., 2013, Moyle et al., 2013, Ballard et al., 2005). An analysis of engagement is anticipated to help nursing staff by providing them with the tools to enhance opportunities for meaningful activities in people with dementia. The study of engagement will also help researchers to examine and recommend meaningful activities for people with dementia.

1.1 Background

According to Lawton's (Lawton, 1983) "dual-channel" model of engagement, there is an antecedent pattern for positive and negative psychological states or affect in older people. Externally engaging events, such as socializing and partaking in recreational activities, contribute to a positive psychological state or affect. External engagement refers to the mood states, thoughts and behaviours the person has toward a stimulus peripheral to them. In contrast, a person's focus toward an internalised stimulus can include cognition, memory or a somatic sign. Intrapersonal elements such as health, personality and self-esteem are hypothesised to have an influence on negative affect. Furthermore, Lawton et al. (1995) recommend that the "dual-channel" model of engagement should be considered in relation to the valences of antecedent events and affective outcomes. In essence, engaged people with dementia are physically, cognitively and emotionally connected through both external and internal stimulus. Event-affect relationships are found to be more prominent between positive valent

events and positive affect, as well as negative valent events and negative affect, compared with cross relationships (Lawton et al., 1995).

1.2 The Observational Method of Engagement (OME)

Lawton's work has contributed greatly to researchers' comprehension of engagement; however, it continues to be difficult to quantify engagement in people with dementia given the limited work that has examined engagement in this population. A notable engagement assessment measure includes the Observational Method of Engagement (OME) developed by Cohen-Mansfield and colleagues (Cohen-Mansfield et al., 2009). The OME is based on the Comprehensive Process Model of Engagement that postulates engagement with a stimulus is shaped by three attributes: the environment, the person and the stimulus. Environmental attributes include the location, people in the environment, timing, level of lighting, noise, temperature and the way the person is introduced to the stimulus. The characteristics and traits of the person include their demographics, past leisure pursuits (i.e. hobbies and activities) as well as level of apathy, cognition, focus and interest. Stimulus refers to characteristics such as appearance, texture, movement, any sound it makes, as well as any social qualities that may affect engagement. It is hypothesised that engagement is influenced by the interaction between the environmental-stimulus and person-stimulus, resulting in the modification of the person's affect, which further changes the presentation of behavioural symptoms. The Comprehensive Process Model of Engagement also suggests that engagement can be measured by an individual's refusal, attention and attitude toward the stimulus (Cohen-Mansfield et al., 2009).

While studies investigating activity engagement in people with dementia have often used the OME as a direct observation measure (Trahan et al., 2014), the use of OME to assess engagement can be fraught with challenges (Jones et al., 2015). First, the OME assesses five different aspects of engagement, each with its own distinct measuring unit. Consequently, it is difficult to ascertain the overall experience of engagement in the absence of an aggregated OME score. Second, expressed emotion

and behaviours toward the stimulus are measured together. This is challenging when cognitive impairment is involved, as a person with dementia can display a low level of emotion due to a reduction in the intensity of their emotional response (i.e., blunted affect), but still remain behaviourally engaged with the stimulus. It is common to observe blunted affect in people with dementia and particularly those with Frontotemporal dementia (Kumfor and Piguet, 2012). Finally, the OME does not appropriately discern social engagement in situations where a person with dementia may engage, interact and talk with family members, staff and other residents via the use of the stimulus as a mean or channel for communication.

1.3 Menorah Park Engagement Scale

The Menorah Park Engagement Scale (MPES) is an observational scale that was developed together with the Montessori-Based Dementia Programme (Camp, 2006). The MPES is designed to assess the type and amount of engagement (i.e., constructive engagement, passive engagement, non-engagement and other engagement). While this scale was developed for people with dementia, it has a limited focus on affective states and social interaction.

1.4 The Revised Index for Social Engagement

The revised Index for Social Engagement (ISE) is another observational scale that assesses positive features of social behaviour (Gerritsen, 2008). This scale was developed for residents in long-term care, but not specifically for people with dementia and, as a result, it has a limited focus on affective states.

1.5 Social Observation Behaviours Residents Index (SOBRI)

A more promising tool is the newly developed Social Observation Behaviours Residents Index (SOBRI) that examines the nature of social interactions in people with dementia (Mabire et al., 2016). The index is based on an ethogram of direct observations that

were reported to consist of 126 behaviours in four categories: (1) social interactions with residents or care staff; (2) self-centred behaviours; (3) stereotypical behaviours; and (4) unclassified behaviours. The authors' preliminary work looked at the social interactions between people with dementia who met for the first time and this research demonstrated the robust psychometric validity of the SOBRI. Using Principal Component Analysis (PCA), the SOBRI was found to measure two components of social behaviours (i.e., those with other residents and with care staff). The SOBRI developers suggested that the scale may be suitable in assessing social behaviours before and after a psychosocial intervention. However, the scale is limited as it does not take into consideration negative social behaviours that are arguably equally important in understanding the true effectiveness of a psychosocial intervention that promotes meaningful activity and engagement. Furthermore, one of the scale items, 'blank stare', was found to be the second highest occurring behaviour. We recommend that this item needs further consideration, as this does not account for the individual's ability to communicate and/or the potential for hallucinations and delusions that have an impact on the person's communication.

1.6 Engagement of a Person with Dementia Scale (EPWDS)

To overcome the aforementioned limitations of the existing scales, a fresh means to manage appraisal of engagement in people with dementia, that takes into consideration both social interaction and activity participation, is needed. This paper reports on a newly developed scale (i.e., EPWDS) that is expected to assess engagement in people with dementia.

The EPWDS was developed based on current literature and previous research work on a video coding tool – the VC-IOE (Jones et al., 2015) – that was used to assess engagement in people with dementia when presented with a social robot. The VC-IOE examines six areas of engagement: emotional, verbal, visual, behavioural, collective and agitation. The VC-IOE takes into consideration the length of the displays of engagement in a video recording. The outcome is elucidated as the relative amount of the video

recording from which the displays of engagement are apparent. Alternatively, the frequency of the manifestations of engagement as per the VC-IOE can be calculated. However, since the length of time for an individual occurrence of engagement can fluctuate substantially, it may not be accurate or meaningful to cogitate the frequency of engagement. Either way, VC-IOE takes considerable time to complete and, as a result, the authors sought to develop a more practical and shorter scale. The EPWDS was therefore constructed to measure behavioural and emotional expressions and responses of people with dementia when presented with a psychosocial activity.

The EPWDS is developed primarily for research involving people with dementia across settings (e.g., acute, community and long-term care). The scale determines if activities are meaningful activities for people with dementia. To capture different expressions of engagement toward an activity, the EPWDS measures five areas of engagement: affect, visual, verbal, behavioural and social. Each area of engagement is evaluated independently but can be collectively interpreted to provide a thorough impression of the person with dementia's engagement toward an activity. Each area includes an item that measures positive engagement and an item that measures disengagement or negative engagement, with a total of 10 items. The EPWDS is used for a minimum observational period of 10 minutes. A baseline comparison of an equivalent period prior to the introduction of the activity can be undertaken to calculate individual change before and during activity. Each item of the EPWDS is measured on a 1 to 5 Likert-type scale, with a "not applicable" option that should only be used when a certain type of engagement is irrelevant or unable to be determined for the person with dementia (e.g., a person who has lost verbal capability after a stroke). If all items across the five subscales of the EPWDS are measured, the total score will range from 10 – 50. The higher the total score, the higher the level of positive engagement exhibited. The lower the total score, the higher the level of disengagement or negative engagement exhibited. Furthermore, a separate question examining the appropriateness of the overall environment for the activity is included to examine and control for environmental effects on engagement. This paper reports on the process involved in establishing content validity and psychometric properties for the EPWDS.

2 THE STUDY

2.1 Aim

The purpose of the study was to establish content validity and psychometric properties for the EPWDS. The study received ethics approval from the University Human Research Ethics Committee (Reference Number: NRS/03/14 and 2015/743).

2.2 Methodology – Content Validity

The Delphi technique was used to establish content validity of the EPWDS. The Delphi technique is a research method using several rounds of communication among experts to establish consensus for a real-world problem (Hsu and Sandford, 2007). The technique seeks to obtain the opinions of experts through a series of structured questionnaires delivered over multiple iterations until consensus is reached. Responses and opinions from each Delphi round are summarised by the researchers and represented to the experts for them to respond to. The multi-stage process combines experts' opinions into group census while maintaining anonymity among group members. The Delphi technique can be undertaken with large numbers of people or with smaller groups (Powell, 2003). The Delphi technique is one of the preferred techniques for determining content validity, as other methodologies, such as focus groups and consensus conference techniques, often force experts into consensus and are problematic when one or a small number of vocal experts dominate the consensus process (Jairath and Weinstein, 1994).

2.2.1 Selection of Delphi Experts

Purposive sampling was used to select a panel of experts. A total of 32 people from Australia and internationally were invited to be a Delphi expert panellist based on the following criteria:

- a person preferably with early stage or young onset dementia, or
- a family carer of a person with dementia, or
- a researcher with demonstrated expertise related to engagement and dementia, or
- a health professional with expertise in dementia.

Potential expert panellists were recruited by email or telephone call. Each were provided with a study information sheet that explained the objectives of the EPWDS, Delphi process, expectations regarding participation, as well as risks and benefits of the study. On verbal agreement to be a panel member, expert panellists were asked to sign a written informed consent form.

2.2.2 Data Collection & Instruments

The Delphi study consisted of four phases that were completed from October 2015 to February 2016 (refer to Figure 1). The two rounds of survey took longer than expected due to the Christmas holiday period and the panellists' busy schedules.

Round 1. Expert panellists were sent an email consisting of: (a) a password protected five-minute online video URL link showing a person with dementia participating in a psychosocial activity; (b) the EPWDS including instructions for completing and scoring the EPWDS; and (c) a questionnaire seeking expert panellists':

- demographic information (round 1 only);
- opinions on the EPWDS in terms of its five subscales of affect, visual, verbal, behavioural and social, units of measurement (i.e., response options), instructions; as well as
- views on whether the scale items were appropriate and valid measures of the various aspects of engagement.

Panellists were invited to watch the short video and then review the scale in relation to the video content, as well as to answer the questionnaire. Data collected from Round 1 were analysed and used to revise the EPWDS.

Round 2. The original and revised EPWDS, together with a detailed list of revisions made to the original scale and the questionnaire, were sent to the expert panellists. Panellists were once again invited to complete the opinion questionnaire by marking their level of agreement on a 5-point Likert-type scale of (1) 'strongly disagree' to (5) 'strongly agree' for each of the revisions and the revised EPWDS. The panellists were also asked to provide additional comments and suggestions, if any, on the revisions and the revised EPWDS.

2.2.3 Data Analysis

Data were analysed by computing the means and standard deviations using IBM SPSS Statistics for Windows Version 23.0 (Armonk, NY: IBM Corp.). Each revision to the EPWDS was only accepted if the overall agreement was greater than an average of 3 on the 5-point Likert-type scale and the standard deviation permitted a positive response. Similarly, the overall level of agreement with the revised EPWDS was calculated and the revised EPWDS was accepted if the expert panellists demonstrated a consensus of responses greater than or equal to 3 on the 5-point Likert-type scale.

2.3 Methodology – Psychometric Properties

Direct recorded observations (i.e., 10-minutes per participant) of 131 participants, from nine Australian long-term aged care facilities using the EPWDS, were undertaken. These videos were part of a larger project where residents were presented with PARO – a therapeutic, interactive, robotic seal – between 2015 - 2016 (Moyle et al., 2017). Participants were aged between 61 and 101 (*mean* = 83.97, *SD* 8.29) and 26.7% were male. Besides a confirmed dementia diagnosis, cognitive function of all participants was measured by The Rowland Universal Dementia Assessment Scale (Storey et al., 2004), ranging between 0 – 23 (*M* = 6.53, *SD* = 6.53).

2.3.1 Procedures

Four raters, experienced with video coding and analysing videos of people with dementia, were recruited and trained in the use of the EPWDS. Each rater independently watched the 10-minute video for each participant and completed the EPWDS to assess engagement. On completion, all raters were asked to complete the EPWDS again for the first 20 percent of the participants (i.e., first 27 cases) to evaluate test-retest reliability. The raters had no access to the original completed EPWDS for these 27 cases. In addition, to assess construct validity (i.e., convergent and discriminant) of the EPWDS, two raters completed the psychometrically sound Person-Environment Apathy Rating (PEAR) scale (Jao et al., 2016) for the first 20 percent of the participants (i.e., first 27 cases). In the PEAR scale, the environmental stimulation was measured by observing stimulation clarity, stimulation strength, stimulation specificity, interaction involvement, physical accessibility and environmental feedback and was expected to be positively associated with engagement. Apathy was measured by observing facial expressions, eye contact, physical engagement, purposeful activity, verbal tone and verbal expression and was expected to be negatively associated with engagement.

2.3.2 Data Analysis

Data from the completed EPWDS were entered into IBM SPSS Statistics for Windows Version 23.0 (Armonk, NY: IBM Corp.). There was no missing data. To assess the internal consistency of the EPWDS, the average score across the four raters was computed for each item. Cronbach's alpha was then calculated using 131 cases, with interpretation of the alpha coefficients considered as follows: below .70 = poor; between .70 and .79 = fair; between .80 to .89 = good; and above .90 = excellent (Tate, 2010).

Inter-rater reliability coefficients were computed using two-way mixed, consistency type, Intraclass Correlations (*ICC*), to assess the degree to which the four raters consistently agreed on ratings of the different dimensions of engagement. The

ICC was calculated on single items, subscales and the total engagement score. According to Tate (2010), *ICC* values lower than .40 can be interpreted as poor; between .40 and .59 as fair; between .60 and .74 as good; and above .75 as excellent.

Test-retest reliability was calculated for the first 20 percent of the participants (i.e., 27 cases). As with internal consistency calculations, a single score was computed for each item by averaging the scores from the four raters. Pearson's *r* coefficient was calculated based on the average item score to compare consistency between the repeated tests. Pearson's *r* coefficients are interpreted in a similar manner to Cronbach's alpha coefficients outlined previously.

Finally, to assess construct validity (i.e., convergent and discriminant) of the EPWDS, inter-rater reliability was first calculated for the PEAR subscale between raters to ensure consistency. Pearson's *r* coefficients were calculated using the average score for each subscale (and total score where appropriate) for the EPWDS and PEAR scale. A significantly positive association between the environment subscale of PEAR and the EPWDS would indicate sound convergent validity and a significantly negative association between the apathy subscale of PEAR and the EPWDS would indicate sound discriminant validity.

3 RESULTS

3.1 Content Validity Testing

A total of 15 expert panellists who met the selection criteria responded to the invitation and participated in the Delphi technique. The panel consisted of predominately of females who were aged between 41-50 years, had doctoral qualifications and were experienced dementia researchers, with an average 14.3 years (*SD* = 11.3) research experience (refer to Table 1). All of the participating dementia researchers had clinical expertise and had either previously or were currently working with people living with dementia. The panel also included a dementia carer and a dementia healthcare professional, but no persons with dementia agreed to participate.

Results from the Round 1 questionnaire generally showed consensus for the five subscales of affect, visual, verbal, behavioural and social, units of measurement, instructions and use of EPWDS. The average consensus for the 35-items in the questionnaire ranged from 3.00 to 4.53 (*SD* .52 – 1.55) (refer to Table 2). The research team reviewed the written comments provided by the panel of experts and discussed any areas where consensus was challenged. Where consensus deemed changes appropriate, recommended changes were made to the original EPWDS. The key areas of revision were as follows:

- The introduction and instructions on the use of the EPWDS were revised to provide further clarity to the aim and purpose of the scale, as well as how to use and score using the scale.
- Statements were added for users to record observation details of the psychosocial activity, which included comments about the appropriateness of the environment as this has the potential to have an impact on engagement.
- An agitation subscale was removed, as it was perceived as a negative behavioural expression and this was already assessed by the behavioural subscale.
- Each subscale was revised to comprise of two questions (i.e., one positive and one negative engagement, with clear examples of each of these responses) to reflect equal emphasis on the various areas of engagement.
- The 0-10 Visual Analogue Scale (VAS) was replaced with a 5-point Likert-type scale as the measuring unit. While both measuring options provide comparable responsiveness and are statistically sound, the Likert-type scale, with anchor points, was deemed to be more suitable for the purpose of the EPWDS due to its inherent practicality and ease of administration and interpretation compared with the VAS (Hasson and Arnetz, 2005). This change also provided consistency for the scale anchors in the EPWDS.
- The collective engagement subscale was renamed as social engagement, as the intention was to reflect participants' use of the psychosocial activity as a means to socially engage with others.

Results from the Round 2 questionnaire reflected strong consensus for the five subscales of affect, visual, verbal, behavioural and social, units of measurement, instructions and use of the revised EPWDS. The average consensus for the 26 revisions in the questionnaire ranged from 3.71 to 4.85 ($SD = .15 - 1.19$) (refer to Table 3). The revised version of the EPWDS achieved an average overall scale consensus of 4.07 ($SD = .47$), reflecting 81.4% agreement among the panel of experts. Following this, some minor editorial revisions were made to the EPWDS. A copy of the final EPWDS is included at the end of this paper (refer to Appendix A).

3.2 Psychometric Properties Testing

Internal consistency for the EPWDS was excellent, with $\alpha = .94$ indicating that the 10 items are contributing to the measurement of the same construct. Additionally, item-total statistics indicated that alpha coefficients would not be significantly improved by the removal of any of the items. Inter-rater reliability scores as measured by ICC ranged from .75 to .96, $p < .001$ on the single item scores, which are all within the excellent range. All subscale scores were also within the excellent range, with $ICC = .84$ to .95, $p < .001$. The overall total score for engagement also demonstrated excellent inter-rater reliability, with $ICC = .97$, $p < .001$. These coefficients indicate that the coders had a high degree of agreement in the way they coded engagement behaviours of people with dementia using the EPWDS (refer to Table 4). Test-retest reliability for individual items ($r = .80 - .96$, $p < .001$) and subscales ($r = .86 - .95$, $p < .001$) were in the good to excellent range. Test-retest reliability for the overall scale ($r = .95$, $p < .001$) was excellent, suggesting that the use of the EPWDS generates reliable and consistent results when coding was conducted on the same observation (refer to Table 4).

Lastly, good to excellent inter-rater reliability was demonstrated on the PEAR subscales between the two raters, with respective ICC scores of .65 for environment and .87 for apathy. Therefore, the mean scores were taken and Pearson's r coefficients were calculated to evaluate associations between the EPWDS and PEAR subscales. As

demonstrated in Table 5, significant positive associations were found between the PEAR environment subscale and the EPWDS subscales ($p < .01$), as well as the total EPWDS score ($r = .74, p < .01$), indicating sound convergent validity. Sound discriminant validity was demonstrated, with significant negative associations found between the PEAR apathy subscale and the EPWDS subscales ($p < .01$). Further, a significant negative association was also found between the EPWDS total score and the PEAR apathy subscale ($r = -.76, p < .01$).

4 DISCUSSION

It is imperative to engage a person with dementia in meaningful activity to enhance wellbeing and this should be a priority in care provision. Due to reduced emotionality (i.e., blunted affect), as well as cognition and communication impairments associated with dementia, it can be challenging to assess engagement responses of a person with dementia toward a psychosocial activity. The Engagement of a Person with Dementia Scale (EPWDS) was therefore developed in response to our research that observes the responses and engagement toward psychosocial activities of a person with dementia. The EPWDS can assess the expressions and responses of the person through either video or natural observation in the field.

The results from this Delphi study validated the concept of the EPWDS and its content that addresses affective, visual, verbal, behavioural and social engagement in people with dementia. The results demonstrated consensus by the Delphi expert panellists and the EPWDS was considered to be a potentially valuable resource for assessing engagement in people with dementia. Furthermore, robust psychometrics for the EPWDS – in terms of internal consistency, inter-rater reliability, test-retest reliability and construct validity – were established when applied to people with dementia living in long-term care. The scale can lower ambiguity in decision-making processes as well as improve objectivity of the different areas of engagement. Furthermore, the scale's distinct consideration of social engagement together with the collation of different prior conceptualizations and measurement of engagement into a total score enables a

comprehensive and meaningful understanding of engagement outcomes. Further, the scale can assess the presence and absence; the nature (i.e., positive or negative affect); the intensity; as well as the target of engagement. These allow the provision of a thorough, valid and reliable measurement of the effect of psychosocial activities on engagement, as well as the quality of the experience. The results suggest that the EPWDS could facilitate translation of meaningful psychosocial activities into evidence-based practice.

Simple in its form and content, the EPWDS draws on knowledge that may be seemingly apparent to many healthcare professionals. Nonetheless, it tackles an unaddressed need for engagement in people with dementia to be measured in a standardized manner. Furthermore, the EPWDS could potentially constitute a valuable addition to the professional resources of dementia researchers and healthcare professionals and to support, as well as enhance, the quality of services in various dementia care settings.

4.1 Limitations

Firstly, the results from the Delphi study were theoretical in nature and merely validate the tool's concept. The process was reliant on expert panellists' expertise and honesty. Nevertheless, our panel comprised of distinguished experts in the dementia field with extensive clinical expertise, whom were encouraged to give frank and candid responses by ensuring their anonymity. This is further negated by the robust psychometric properties established for the EPWDS in research. However, the use of the EPWDS in clinical settings should be assessed in future work to ascertain its external validity.

5 CONCLUSIONS

It is important to engage a person with dementia in meaningful activity to enhance wellbeing via the increment of positive affect and enhancement in quality of life. This should be a priority in care provision. The Engagement of a Person with Dementia Scale (EPWDS) assesses the behavioural and emotional expressions and responses of engagement by people with dementia when partaking in a psychosocial activity in five areas: affective, visual, verbal, behavioural and social engagement. In addition to the validation of the concept and content of the EPWDS by the Delphi expert panellists, the EPWDS was also found to be psychometrically sound and a valid and reliable resource for assessing engagement in people with dementia. Testing of the EPWDS in clinical settings other than in research is needed to ascertain its external validity.

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Table 1. Expert Panelist's Demographic Characteristics (*n* = 15)

Variables		%
Gender	Female	66.7
	Male	33.3
Age	31-40 years	13.3
	41-50 years	40.0
	51-60 years	20.0
	61-70 years	26.7
Education Level	Undergraduate	20.0
	PhD	80.0
Dementia Researcher	Yes	86.7
	No	13.3

Table 2. Round 1 Survey Results (n = 15)

Questionnaire Items	Response: 1 (Strongly Disagree) to 5 (Strongly Agree)	
	Mean	Standard Deviation
Scale Dimensions - For people with dementia...		
Affective or emotional response toward an activity is an important aspect of engagement	4.40	0.83
Participation, tone and content of conversation about the activity are important aspects of engagement	4.33	0.82
Alertness and eye gaze toward the activity are important aspects of engagement	4.53	0.52
Behavioural response toward the activity is an important aspect of engagement	4.53	0.74
The use of an activity to instigate social interaction is an important aspect of engagement	3.93	0.96
Agitated behaviour or response toward the activity is an important aspect of engagement	3.40	1.55
Affective Subscale - For people with dementia		
The behaviour and expression criteria appropriately measure affective engagement toward the activity	3.67	0.82
The subscale appropriately measures positive and negative affective engagement toward the activity	3.79	0.89
Overall, the subscale is a valid measure of affective engagement toward the activity	3.50	1.02
Visual Subscale - For people with dementia		
The behaviour and expression criteria appropriately measure visual engagement toward the activity	3.87	0.52
The subscale appropriately measures the presence of visual engagement toward the activity	3.93	0.59
Overall, the subscale is a valid measure of visual engagement toward the activity	3.93	0.62
Verbal Subscale - For people with dementia		
The behaviour and expression criteria is an appropriate measure of verbal engagement toward the activity	3.64	0.74
The subscale is an appropriate measure of positive and negative verbal engagement toward the activity	3.31	0.63
Overall, the subscale is a valid measure of verbal engagement toward the activity	3.23	0.73
Behavioural Subscale - For people with dementia		
The behaviour and expression criteria appropriately measures behavioural engagement toward the activity	3.54	0.66

Running Head: Engagement of a Person with Dementia Scale

The subscale appropriately measures positive and negative behavioural engagement toward the activity	3.62	0.65
Overall, the subscale is a valid measure of behavioural engagement toward the activity	3.46	0.78
Collective Subscale - For people with dementia		
The behaviour and expression criteria appropriately measures collective engagement with others toward the activity	3.15	0.80
The subscale appropriately measures the presence of collective engagement with others toward the activity	3.15	0.80
Overall, the subscale is a valid measure of collective engagement with others toward the activity	3.08	0.86
Agitation Subscale - For people with dementia		
The behaviour and expression criteria appropriately measures an agitation response toward the activity	3.75	0.87
The subscale appropriately measures the presence of an agitation response toward the activity	3.67	0.65
Overall, the subscale is a valid measure of an agitation response toward the activity	3.67	0.65
The unit of measure used on the EPWDS is...		
Easy to use	3.69	1.18
Practically useful	3.77	0.93
Methodologically sound	3.54	0.88
Appropriate	3.54	0.97
Sensitive to changes	3.69	0.75
The EPWDS instructions are ...		
Easy to understand	3.87	0.52
Simple to follow	3.87	0.83
Appropriate	3.80	0.86
Overall, the current form of the EPWDS can...		
Serve as a valid measure of the engagement level for people with dementia	3.27	0.65
Generate a reliable measure of the engagement level for people with dementia	3.00	0.77
Generate a practically useful and informative measure of the engagement level for people with dementia	3.45	0.69

Table 3. Round 2 Survey Results (n = 15)

Questionnaire Item Information Sent to Participants	Response: 1 (Strongly Disagree) to 5 (Strongly Agree)	
	Mean	Standard Deviation
Introduction & Instructions		
The aim and purpose of the EPWDS have been reworded.	4.43	0.76
A paragraph has been added to explain the five dimensions of engagement measured by the EPWDS.	4.14	0.77
Under “ <i>How to use the scale</i> ”, more detailed instructions and explanation have been provided for the use and application of the EPWDS.	4.46	0.52
Under “ <i>How to score the scale</i> ”, more detailed instructions and explanation have been provided for the reverse-scoring procedure.	4.29	0.83
Observation Details		
A section has been added to record details of the observation and psychosocial activity to assist in the interpretation of the total score generated by the scoring of the EPWDS.	4.43	0.51
To examine and control for environmental effects on the engagement level of the person with dementia, a measure for the appropriateness of the environment has been added.	4.14	1.03
Scale Dimensions and Measuring Unit of the EPWDS		
Agitation has been removed as a dimension or expression of negative engagement.	4.36	0.84
Each dimension (i.e., affective, visual, verbal, behavioural, and social engagement) now consists of a subscale that measures positive engagement and a subscale that measures disengagement or negative engagement.	4.69	0.48
The measuring unit has been changed to a 5-point Likert scale from 1 (Strongly Disagree) to 5 (Strongly Agree).	3.71	0.15
A “not applicable” option has been added to reflect dimension of engagement that is irrelevant or unable to be determined for the person of dementia.	4.85	0.38
Affective Engagement		
This dimension has been renamed as “affective engagement”.	4.64	0.63
Examples of positive affect have been included.	4.57	0.51
Singing has been taken out as an expression of positive affect.	4.21	0.89
Apathy has been included as an example of negative affect.	4.21	1.05
Additional examples have been added for the expressions of negative affect.	4.10	0.99

Running Head: Engagement of a Person with Dementia Scale

Visual Engagement

Alertness has been removed as an expression of visual engagement.	4.43	0.76
“Closed eyes” has been included as an expression of negative visual engagement.	4.57	0.51
The target of visual engagement is specified to be “ <i>the activity, the materials used, or the persons involved</i> ”.	4.43	0.65

Verbal Engagement

Positive and negative verbal engagement consists of examples of both verbal and non-verbal expressions.	4.21	1.05
The target of verbal engagement is specified to be “ <i>the activity, the materials used, or the persons involved</i> ”.	4.43	0.85

Behavioural Engagement

“Respond appropriately” is removed as an expression of positive behavioural engagement.	4.77	0.44
“Following instruction” is removed as an expression of positive behavioural engagement.	4.36	0.74
The target of behavioural engagement is specified to be “ <i>the activity, the materials used, or the persons involved</i> ”.	4.57	0.65

Social Engagement

“Collective Engagement” has been renamed as “Social Engagement”.	4.71	0.47
Item 9 has been reworded to reflect an expression of positive social engagement.	4.64	0.63
Item 10 has been added to measure an expression of negative social engagement.	3.92	1.19

Table 4. Inter-rater reliability (ICC) and test-retest (r) results for the Engagement of Person with Dementia Scale

Rating item	Inter-rater reliability (n = 131 videos)		Test-retest reliability (n = 27 videos)	
	ICC	CI (95%)	Pearson's r	CI (95%)
Affective Engagement	.90	.87~.93	.89	.77~.95
Positive affect	.87	.83~.90	.87	.73~.94
Negative affect	.75	.67~.81	.83	.66~.92
Visual Engagement	.94	.93~.96	.92	.83~.96
Visually engaged	.94	.92~.96	.92	.83~.96
Visually avoidant	.89	.85~.92	.90	.79~.95
Verbal Engagement	.93	.91~.95	.92	.83~.96
Verbally engaged	.90	.87~.92	.92	.83~.96
Verbally avoidant	.91	.88~.93	.86	.71~.94
Behavioural Engagement	.95	.94~.96	.95	.89~.98
Behaviourally engaged	.96	.94~.97	.96	.91~.98
Behaviourally avoidant	.89	.85~.92	.90	.79~.95
Social Engagement	.84	.79~.88	.86	.71~.94
Socially engaged	.84	.79~.88	.86	.71~.94
Socially disruptive	.82	.76~.87	.80	.60~.91
TOTAL Engagement	.97	.97~.98	.95	.89~.98

Note. All coefficients were significant at $p < .001$

Table 5. Associations between the EPWDS and PEAR subscales (n = 27)

	Affective engagement	Visual engagement	Verbal engagement	Behavioural engagement	Social engagement	Total engagement
PEAR Environment	.61*	.68*	.71*	.63*	.82*	.74*
PEAR Apathy	-.73*	-.78*	-.71*	-.63*	-.65*	-.76*

Note. * $p < .01$

Appendix A: Engagement of a Person with Dementia Scale (EPWDS)

The Engagement of a Person with Dementia Scale (EPWDS) measures the behavioural and emotional expressions and responses of people with dementia when presented with a psychosocial activity (i.e. non-pharmacological). The scale is designed to examine whether an individual with dementia exhibits an emotional or behavioural expression/response of engagement with, in, or following the introduction of the activity.

To capture different expressions of engagement towards a psychosocial activity, the EPWDS measures five dimensions of engagement: **affective, visual, verbal, behavioural, and social**. Each dimension of engagement should be assessed separately but interpreted collectively to generate a comprehensive overview of the person with dementia's experience of engagement toward the stimulus. Every dimension consists of a subscale that measures positive engagement and a subscale that measures disengagement or negative engagement. The EPWDS acknowledges that not all psychosocial activity involves the five dimensions of engagement, but a low score on a certain dimension of engagement may suggest a limitation of the psychosocial activity for the person with dementia assessed.

How to use the scale:

- The EPWDS is developed primarily for research with people with dementia across settings (e.g. acute, community and long-term care).
- It is recommended that the EPWDS be used for observational periods with minimum observation duration of 10 minutes.
- The EPWDS can be used to establish a baseline comparison prior to the introduction of the psychosocial activity.
- Each item is measured on a 1 - 5 Likert scale. Please tick a value for each of the items.
- The “not applicable” option should only be used when a certain type of engagement is irrelevant or unable to be determined for the person with dementia (e.g., a person who has lost verbal capability after a stroke).

How to score the scale:

Running Head: Engagement of a Person with Dementia Scale

- Items 2, 4, 6, 8, and 10 are reverse scored items. After scoring the observational period on the EPWDS, simply reverse the numerical scoring of items 2, 4, 6, 8 and 10. This means that, a score of 5 becomes 1, 4 becomes 2, 3 remains as 3, 2 becomes 4 and 1 becomes 5.
- After reverse scoring items 2, 4, 6, 8, and 10, add the scores for all 10 items to get an overall measure of engagement for the person with dementia.
- If all items across the five dimensions of the EPWDS are measured, the total score will range from 10 – 50. The higher the total score, the higher the level of positive engagement exhibited by the person with dementia. The lower the total score, the higher the level of disengagement or negative engagement exhibited by the person with dementia.
- To examine and control for environmental effects on the engagement level of the person with dementia, an inter-correlation analysis can be conducted between the total EPWDS score and the environmental rating under the section titled “*Details of Observation Period and Psychosocial Activity*”.

Details of Observation Period and Psychosocial Activity:

Start Time of Observation Period: _____

End Time of Observation Period: _____

Total Duration of Observation Period: _____

Type of Psychosocial Activity: _____

Group or Individual Psychosocial Activity: _____

Location of Psychosocial Activity: _____

Appropriateness of the Environment:

Please indicate the extent to which you agree or disagree to the following statement:

The overall environment (e.g., lighting, noise level, and presence of other) is appropriate for the target psychosocial activity to induce positive engagement in people with dementia.

1	2	3	4	5
<input type="checkbox"/>				
Strongly disagree				Strongly agree

Running Head: Engagement of a Person with Dementia Scale

<u>Affective Engagement</u>							
Please indicate the extent to which you agree or disagree to the following statements: the person with dementia...							
1.	Displays positive affect such as pleasure, contentment or excitement (e.g., smiling, laughing, delight, joy, interest and/or enthusiasm).	1 <input type="checkbox"/> Strongly disagree	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/> Strongly agree	N/A <input type="checkbox"/>
2.	Displays negative affect such as apathy, anger, anxiety, fear, or sadness (e.g., disinterest, distressed, restlessness, repetitive rubbing of limbs or torso, repeated movement, frowning, crying, moaning, and/or yelling).	1 <input type="checkbox"/> Strongly disagree	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/> Strongly agree	Not applicable

<u>Visual Engagement</u>							
Please indicate the extent to which you agree or disagree to the following statements: the person with dementia...							

Running Head: Engagement of a Person with Dementia Scale

3.	Maintains eye contact with the activity, materials used, or the person/s involved.	<table border="0"> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>Strongly disagree</td> <td></td> <td></td> <td></td> <td>Strongly agree</td> </tr> </table>	1	2	3	4	5	<input type="checkbox"/>	Strongly disagree				Strongly agree	N/A <input type="checkbox"/>				
1	2	3	4	5														
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>														
Strongly disagree				Strongly agree														
4.	Appears inattentive, has an unfocused stare or turns head/eyes away from the activity, materials used, or the person/s involved.	<table border="0"> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>Strongly disagree</td> <td></td> <td></td> <td></td> <td>Strongly agree</td> </tr> </table>	1	2	3	4	5	<input type="checkbox"/>	Strongly disagree				Strongly agree	Not applicable				
1	2	3	4	5														
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>														
Strongly disagree				Strongly agree														

<p><u>Verbal Engagement</u></p> <p>Please indicate the extent to which you agree or disagree to the following statements: the person with dementia...</p>																		
5.	Initiates, participates, or maintains verbal conversation, sounds or gestures (e.g., nodding) in response to the activity, or the materials used, or the person/s involved.	<table border="0"> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>Strongly disagree</td> <td></td> <td></td> <td></td> <td>Strongly agree</td> </tr> </table>	1	2	3	4	5	<input type="checkbox"/>	Strongly disagree				Strongly agree					
1	2	3	4	5														
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>														
Strongly disagree				Strongly agree														

Running Head: Engagement of a Person with Dementia Scale

	Responds to an activity by avoiding, shoving away, pulling back from, hitting, or mishandling the activity, the material used, or the person/s involved.	<table style="width: 100%; text-align: center;"> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>Strongly disagree</td> <td></td> <td></td> <td></td> <td>Strongly agree</td> </tr> </table>	<input type="checkbox"/>	Strongly disagree				Strongly agree	N/A <input type="checkbox"/> Not applicable				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>									
Strongly disagree				Strongly agree									

		<p><u>Social Engagement</u></p> <p>Please indicate the extent to which you agree or disagree to the following statements: the person with dementia...</p>																
9.	Uses the activity or the material/s to encourage others to interact, or as a communication channel to interact and talk with others (e.g., staff and other residents).	<table style="width: 100%; text-align: center;"> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>Strongly disagree</td> <td></td> <td></td> <td></td> <td>Strongly agree</td> </tr> </table>	1	2	3	4	5	<input type="checkbox"/>	Strongly disagree				Strongly agree	N/A <input type="checkbox"/>				
1	2	3	4	5														
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>														
Strongly disagree				Strongly agree														
10.	In response to the activity, is distracting or disrupting others (e.g., staff/facilitator and other residents).	<table style="width: 100%; text-align: center;"> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>Strongly disagree</td> <td></td> <td></td> <td></td> <td>Strongly agree</td> </tr> </table>	1	2	3	4	5	<input type="checkbox"/>	Strongly disagree				Strongly agree	Not applicable				
1	2	3	4	5														
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>														
Strongly disagree				Strongly agree														

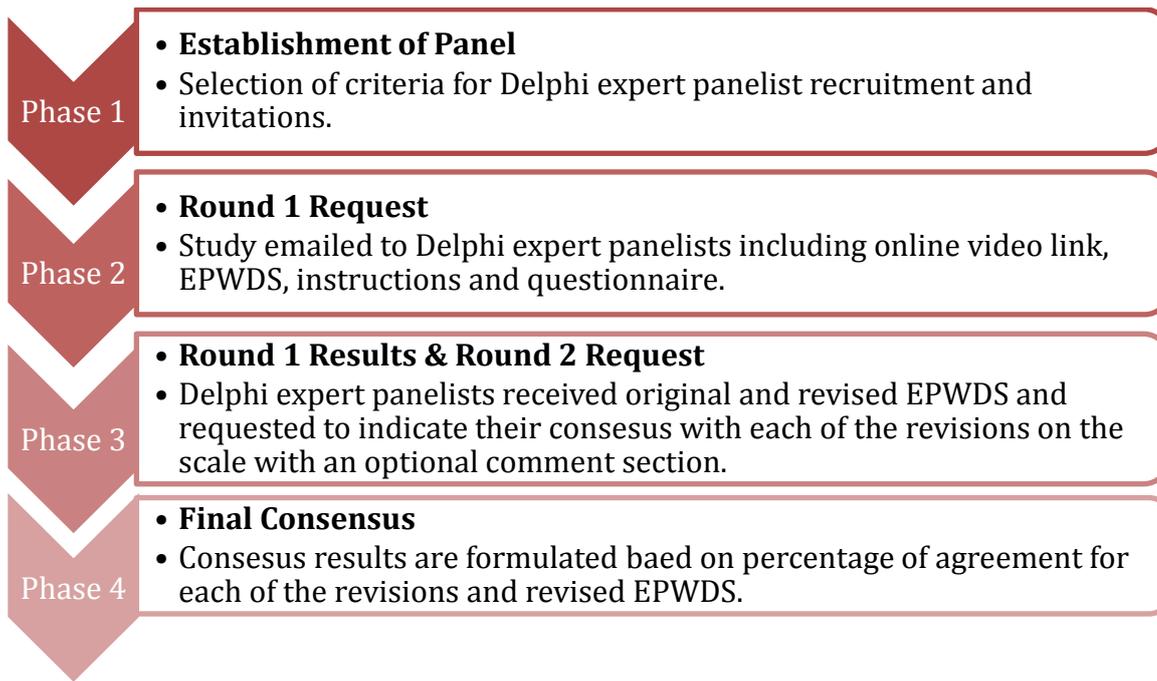


Figure 1. Delphi Study Method Summary Flowchart.