

# Evaluating positive experiences of very severe dementia patients

***Citation for published version (APA):***

Pee, de, J., Hoonhout, H. C. M., Mason, J., Weijts, T., Bergman, T., & Kort, de, Y. A. W. (2013). *Evaluating positive experiences of very severe dementia patients*. Paper presented at CHI 2013 Workshop on Designing For- and With- Vulnerable People, April 27-May 2, 2013, Paris, France, Paris, France.

***Document status and date:***

Published: 01/01/2013

***Document Version:***

Accepted manuscript including changes made at the peer-review stage

***Please check the document version of this publication:***

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

***General rights***

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

[www.tue.nl/taverne](http://www.tue.nl/taverne)

***Take down policy***

If you believe that this document breaches copyright please contact us at:

[openaccess@tue.nl](mailto:openaccess@tue.nl)

providing details and we will investigate your claim.

---

# Evaluating Positive Experiences of Very Severe Dementia Patients

**Jente de Pee**

Philips Research  
Human Interaction & Experiences  
High Tech Campus 34  
5656 AE Eindhoven  
The Netherlands  
Jente.de.Pee@philips.com

**Jettie Hoonhout**

Philips Research  
Human Interaction & Experiences  
High Tech Campus 34  
5656 AE Eindhoven  
The Netherlands  
Jettie.Hoonhout@philips.com

**Jon Mason**

Philips Research  
Human Interaction & Experiences  
High Tech Campus 34  
5656 AE Eindhoven  
The Netherlands  
Jon.Mason@philips.com

**Tanja Weijts**

Vitalis Vonderhof  
Activiteiten Begeleiding  
Bernhardplaats 1  
5616 TG Eindhoven  
The Netherlands  
T.Weijts@vitalisgroep.nl

**Tom Bergman**

Philips Research  
Visual Experiences  
High Tech Campus 34  
5656 AE Eindhoven  
The Netherlands  
Tom.Bergman@philips.com

**Yvonne de Kort**

Eindhoven University of Technology  
Human-Technology Interaction  
PO Box 513  
5600 MB Eindhoven  
The Netherlands  
Y.A.W.d.Kort@tue.nl

**Abstract**

We developed a Snoezelen application to promote the wellbeing of people with severe dementia. During a Snoezelen session, patients are provided with positive and pleasurable experiences, through a combination of visual, auditory, olfactory, and haptic stimuli. Because no measure to evaluate appreciation or enjoyment by this target group themselves could be found, a new observation measure was created and compared to existing proxy measures in a visual stimulation study based on the Snoezelen philosophy. This measure contains three domain scales, Attention, Arousal, and Valence; two (Attention and Arousal) were sensitive enough to capture an effect, or at least a trend towards an effect, of stimulus condition. This finding is seen as promising for the further development of these kinds of observational measures for testing designs for and with this target group.

**Author Keywords**

Alzheimer's disease, Dementia, Explorative study, Observation method, Positive affect, Snoezelen, Sensory experience, Wellbeing.

**ACM Classification Keywords**

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

## **Introduction**

The number of people suffering from dementia is growing rapidly. In 2010 this number was about 36 million people worldwide, while this number is expected to rise to more than 115 million by 2050 [2]. People with dementia can go through different stages of cognitive decline during which their abilities to remember, speak, think, and make decisions deteriorate. In the final stage, apathetic and aggressive behaviors are common and people eventually lose the ability to respond to their environment and to control movement [1]. Their deteriorating mental and physical abilities do not only make people with severe dementia vulnerable health-wise, but their declining communication skills also make it difficult to determine what they like and to take this into account when designing for them.

Since there is no known cure for dementia, promoting wellbeing and maintaining an optimal quality of life has become the main focus in dementia care [8]. A popular means to promote the wellbeing of people with very severe dementia is Snoezelen, or multi-sensory stimulation [3, 14, 16]. During a Snoezelen session, patients are provided with positive and pleasurable experiences, through a combination of visual, auditory, olfactory, and haptic stimuli.

Philips Research has developed a Snoezel application, the Snoezel box, which needed to be evaluated. However, no measure could be found [7] to assess the appreciation or enjoyment of the application by the target group themselves: people with severe dementia.

While many studies reported positive effects of the Snoezelen approach with other target groups (e.g.

people with less severe dementia), the measures they applied often relied on self-report, of which our target group is not capable any longer. Also, many measures to determine the affective response of this group to stimuli mainly focus on negative experiences rather than on positive ones. The Interact [4] measure seemed to come close to the measure we were looking for. However, it relies on the interpretation of caregivers, does not capture the participant's behavior in the moment but instead evaluates a session as a whole afterwards, and not all items were applicable to our specific target group and test setting. However, we did use the Interact as a benchmark measure for our new direct observation scale.

Hence, the goal of the present study became to develop a tool for testing designs for and with people with very severe dementia. Since this target group often is not able to communicate through language anymore, this measure tunes into the modes of communication that they still have at their disposal to determine what they find pleasurable. A structured behavioral observation scale was created and compared to the Interact questionnaire by applying both measures in a visual stimulation study based on the Snoezelen philosophy.

## **Design**

The study had a 3 (type of intervention: Snoezel box vs. Positive affect DVD vs. control) X 3 (repeated sessions) design. The order in which the participants received the three different types of interventions was assigned pseudo-randomly: Because of the vulnerable target group (see high dropout rates in related studies [3, 6, 15, 16]) and the accompanying uncertainty regarding the total number of sessions a participant would be able to participate in, patients participated in

three "rounds" in which the three different conditions were randomly assigned to them. This ensured that the experiment data would include a fair distribution of conditions per participant, even when a participant would drop out early.

### **Participants**

Four (female) participants with very severe dementia, aged between 77 and 94, participated in this study. All participants were living at the closed dementia ward of care center Vitalis Vonderhof in Eindhoven and were selected by their occupational therapist to join the study, on basis of their daily behavior and anticipated susceptibility to visual stimulation. All participants were wheelchair-bound. The guardians of the participants were informed about the goal and set-up of the study and gave their consent for letting their relative take part in the study.

#### *Snoezel box*

The Snoezel box is a prototype developed by Philips Research, about the size of a shoebox, which is designed to be a portable Snoezelen application. It includes a color projection wheel with LEDs, which projects moving colored light patterns on the wall and ceiling adjacent to the device. Its settings, e.g. the speed, brightness and color scheme, can be adjusted to the preferences of the occupational therapist (and hence to the patient's preferences). For the current study, one basic scenario suiting the target group was created in agreement with the occupational therapist. This scenario was used for all participants in the study.

### **Manipulations**

The experiment consisted of three conditions: the Snoezel box condition, the TV condition, and the

Control condition. Every session started with a 6-minute baseline in which the participant was sitting in a dim room without visual stimulation from either the Snoezel box or the TV.

In the Snoezel box condition, after the baseline, the Snoezel box was turned on (14 minutes), projecting different forms of colored dynamic light in a slow pace on one of the walls and the adjacent part of the ceiling. In the TV condition, after the baseline, a segment of 14 minutes from the movie March of the Penguins (2006), in which mainly young penguins are shown, was displayed on the television. Movies are a recommended means to elicit positive affect [11, 12, 17], have been used in various studies [5, 9, 10, 11], and similar videos were used during the existing Snoezelen sessions at Vitalis Vonderhof. In the Control condition, after the baseline, the Snoezel box and the television were both left turned off. The participant was just sitting in the quiet room with dimmed lighting for another 14 minutes.

### **Measurements**

#### *Observational measure*

The items for the new observation scale were selected and adjusted from or inspired by existing measures and adapted such that they appeared relevant to measuring appreciation or positive affect, and appropriate for this specific target group, e.g. "Hand movements, quick/slow" and "Talking, positive/neutral/negative". The selection of items for the final set was based on pilot observations of the target group in Snoezel group sessions and in the living room at Vitalis Vonderhof. They reflected two (of the three) underlying dimensions of emotion [13]: Pleasantness-unpleasantness and Degree of arousal. The third factor, Dominance-

submissiveness, was replaced by Attention as the stimuli provided in the study did not ask for any influence or control from the participant but were expected to be able to capture the attention of the participant. Accordingly, the units in the developed behavioral observation scheme covered behaviors in the domains Attention (alertness-apathy), Arousal (arousal-calmness), and Valence (positive affect-negative affect).

The behavioral observations were conducted by the researcher on basis of video tapes of the sessions capturing the participant's face and upper body. The behaviors were rated in time windows of 2 minutes, based on pilot observations. As explained before, every session took 20 minutes; 6 minutes of baseline and 14 minutes of intervention. Each domain scale, Attention, Arousal, and Valence, consisted of several items (e.g. "Head movement, quick/slow/not moving"), which could be scored 0 (low), 0.5 (medium), or 1 (high) for Attention and Arousal, and -1 (negative), 0 (neutral), and 1 (positive) for Valence. For both the baseline and intervention phases scores per time window were added resulting in a total score for Attention, Arousal, and Valence score, thus rendering 6 behavior scores per participant per session.

#### *Proxy measure (control measure)*

The Interact During and Interact Short [4] were used for concurrent validity in the present study. The Interact is a proxy questionnaire especially created for assessing Snoezelen sessions. It was designed to record behavior during these sessions and covers the domains Mood, Speech, Relating to person, relating to environment, Need for prompting, and Stimulation level with 22 items. For each of these items the frequency of

occurrence of a particular behavior (e.g. "Co-operated") is assessed on a five point Likertscale (1 = not at all, to 5 = nearly all the time). The Interact During was completed by the researcher right after watching the videotaped session. The Interact Short is the 12-item version of Interact, and was completed by care center staff concerning a participant's behavior the 10 minutes immediately before a session and the 10 minutes immediately after a session, to establish any observable changes due to the session.

#### **Procedure**

A caregiver -blind to the experimental condition- placed the wheelchair-bound participant on a marked spot at a distance of about 2 meters from the camera, TV, and Snoezel box and left the room. The caregiver was asked to fill in an Interact Short questionnaire and to return in 20 minutes to collect the participant. After 6 minutes of baseline measurement, the researcher entered the room and turned on either the TV (TV condition) or the Snoezel box (Snoezel box condition), or fiddled a bit with the Snoezel box without actually doing anything (Control condition), and went back to the observation booth. After another 14 minutes, the researcher returned to the room, turned off the TV or the Snoezel box, or fiddled a bit with the Snoezel box, and went back to the observation booth. By 'fiddling with the Snoezel box' in the Control condition, the differences in procedure between the three conditions were minimized and the potentially confounding variable social attention was kept equal in all three conditions. After the session the caregiver -still blind to condition- collected the participant. On the way out, the caregiver received a second Interact Short questionnaire. The researcher -blind to Interact Short scores- filled out the Interact During questionnaire and

collected the Interact Short questionnaires afterwards. During the baseline and experimental session the researcher unobtrusively observed participants from a neighboring observation booth via direct video feed.

## **Analysis & Results**

### *Construction of the observation scales*

In order to create a coherent scale for Attention, Arousal, and Valence, first a reliability analysis was run with all selected items for a certain scale included. Those items that would raise the overall Cronbach's  $\alpha$  of the scale if excluded (according to the 'Cronbach's  $\alpha$  if item deleted'-value) were excluded until an acceptable Cronbach's  $\alpha$  of .6-.7 was produced. Additionally, items that correlated negatively with the total scale were excluded from the scale.

The final Attention scale ( $\alpha = .795$ ) contained 6 items: Head (passive/ active), Eyes (open/open-closed /closed), Eyes (following/blank), Talking (yes/no), Touching (with intent /without intent / not touching), and Attention for application (yes/no).

The final Arousal scale ( $\alpha = .677$ ) contained 7 items: Talking (yes/no), Sounds without intent (yes/no), Head (passive/active), Head movement (quick/slow/not moving), Hand movement (quick/slow/not moving), Touching (with intent/without intent / not touching), and Body movement (moving /not moving).

The final Affect scale ( $\alpha = .527$ ) contained 6 items: Sounds without intent (positive/neutral/negative/not), Mouth activity without a goal (yes/no), Hands (tensed/normal), Mouth (tensed/normal), Body movement (rocking/not rocking), and Talking (positive/neutral /negative/not). (See Appendix for the values per item.)

The effect of Stimulus condition (Snoezel box vs. TV vs. Control) on each of the three observation scales, Attention, Arousal, and Valence, was explored by means of Linear Mixed Model (LMM) analyses. Participant was added as subject variable, baseline scores of the respective outcome score were entered as covariate.

## **Sensitivity of the scales**

### *Observation measure*

The effect of Stimulus condition on Attention was significant,  $F(2,35) = 3.43$ ,  $p = .043$ . When comparing means, the TV condition ( $M=22.8$ ,  $SD=1.90$ ) had the highest Attention score followed by the Snoezel box condition ( $M=18.8$ ,  $SD=1.83$ ) and the Control condition ( $M=15.8$ ,  $SD=1.96$ ). Pairwise comparisons showed that the difference between TV and control condition was significant ( $p = .013$ ). The Snoezel box condition did not differ from either the TV ( $p = .132$ ) or the Control condition ( $p = .265$ ).

The effect of condition on Arousal showed a trend towards significance ( $F(2,35) = 2.75$ ,  $p = .078$ ), with the highest mean for the Snoezel box ( $M=12.4$ ,  $SD=1.97$ ), the lowest for the TV ( $M=9.0$ ,  $SD=1.99$ ), with the control condition ( $M=11.5$ ,  $SD=2.00$ ) in between. The difference between the TV and the Snoezel box condition was significant ( $p = .029$ ), the difference between the TV and control condition was not ( $p = .116$ ), and neither was the difference between the Snoezel box and the Control condition ( $p = .556$ ). As the main effect of Stimulus condition was not significant these findings have to be treated as indications only. No effect of Stimulus condition was found on Valence.

#### *Proxy measure*

When applying Linear Mixed Model (LMM) analysis on the Interact Short, the only item that showed an effect of Stimulus condition was 'Talked spontaneously' ( $F(2,38) = 3.41, p = .0432$ ). The Snoezel box ( $M=2.6, SD=0.24$ ) condition showed the highest score, followed by the Control ( $M=2.6, SD=0.24$ ) and the TV ( $M= 1.8, SD=0.25$ ) condition. Pairwise comparisons showed that the TV condition was significantly different from the Snoezel box ( $p=.025$ ) and the Control condition ( $p=.033$ ), while the Snoezel box and the Control condition were not significantly different ( $p=.886$ ).

When applying LMM analysis on the interact During, the only individual item that showed an effect of Stimulus condition was 'Attentive/responding to/focused on activity/objects' ( $F(1,22) = 5.783, p=.025$ ), in favor of the TV condition ( $M=3.4, SD=0.51$ ) compared to the Snoezel box condition ( $M=2.4, SD=0.51$ ). The control condition was excluded from this comparison as in that condition no stimulus was presented to the participant.

#### **Conclusion & Discussion**

The goal of this study was to explore the possibilities to create a tool for testing designs for and with people with very severe dementia. Therefore we researched how we could determine the appreciation of people in this target group– so, basically, how much they enjoy a particular application or entertainment event. In the literature many different measures were found that could be used to investigate related effects, such as mood or agitation, but no measure could fulfill this particular aim. The two measures, structured behavioral observations and proxy measures (Interact

questionnaires), that were explored in this study did not fully succeed in this either, but their exploration produced valuable insights for future development of an "enjoyment" measure for people with very severe dementia. A measure that does not let other people decide for this vulnerable target group what is best for them, but empowers very severe dementia patients by giving them a voice: Since most severe dementia patients are not able to communicate through language anymore, this measure tunes into the modes of communication that they still have at their disposal to determine what they appreciate and find pleasurable.

Altogether, the findings of this study are rather promising. Although the user group was small ( $N=4$ ) and personal variation in displayed behavior was fairly large, three reasonably consistent behavioral item scales were produced. Contrary to most Snoezelen studies, the present study kept the conditions in the three conditions constant except for the type of device that was turned on, resulting in a relatively subtle manipulation. The fact that the developed behavioral item scales were sensitive enough to show an effect of this subtle manipulation is encouraging for the future development of this kind of real-time observational measures for this target group.

A more thorough exploration and investigation, by means of a larger scale study, of behaviors that cover the domains Attention, Arousal, and Valence should be conducted in order to explore and create an appropriate and valid set of behavioral items for each of the three affect scales.

## Acknowledgements

We would like to thank the staff of the care center Vitalis Vonderhof, the participants, and their relatives for their contribution to this project.

## References

- [1] Alzheimer's Association. Seven Stages of Alzheimer's. Retrieved on 10-05-2012 from: [http://www.alz.org/alzheimers\\_disease\\_stages\\_of\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp)
- [2] Alzheimer's Disease International. (2009). World Alzheimer's Report 2009. London, ADI. Retrieved on 10-05-2012 from <http://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf>
- [3] Baillon, S., Van Diepen, E., Prettyman, R., Redman, J., Rooke, N., & Campbell, R. (2004). A comparison of the effects of Snoezelen and reminiscence therapy on the agitated behaviour of patients with dementia. *International Journal of Geriatric Psychiatry*, 19, 1047-1052. DOI: 10.1002/gps.1208
- [4] Baker, R., Holloway, J., Holtkamp, C. C. M., Larsson, A., Hartman, L. C., Pearce, R., (Scherman, B., Johansson, S., Thomas, P. W., Wareing, L. A.,) & Owens, M. (2003). Effects of multi-sensory stimulation for people with dementia. *Journal of Advanced Nursing*, 43(5), 465-477.
- [5] Codispoti, M., Surcinelli, P., Baldaro, B. (2005). Watching emotional movies: Affective reactions and gender differences. *Int. Journal of Psychophysiology*, 69, 90-95.
- [6] Collier, L., McPherson, K., Ellis-Hill, C., Staal, J., & Bucks, R. (2010). Multisensory Stimulation to Improve Functional Performance in Moderate to Severe Dementia - Interim Results. *American Journal of Alzheimer's Disease and Other Dementias*, 25(8), 698-703.
- [7] De Pee, J. (2012). Assessing the Affective State of Dementia Patients. Do Very Severe Alzheimer Patients Benefit from Visual Stimulation? An Explorative Study. (Unpublished master's thesis). Eindhoven University of Technology in collaboration with Philips Research, Eindhoven.
- [8] Ettema, T. P., Dröes, R. M., de Lange, J., Mellenbergh, G. J., & Ribbe, M. W. (2006). QUALIDEM: Development and evaluation of a Dementia Specific Quality of Life Instrument. Scalability, Reliability and Internal Structure. *International Journal of Geriatric Psychiatry*, 22(6), 549-56.
- [9] Fernandez, C., Pascual, J. C., Soler, J., Elices, M., Portella, M. J., & Fernandez-Abascal, E. (2012). Physiological Responses Induced by Emotion-Eliciting Films. *Applied Psychophysiology and Biofeedback*, 37(2), 73-79.
- [10] Gomez, P., Zimmermann, P., Guttormsen-Schar, S., & Danuser, B. (2005). Respiratory responses associated with affective processing of film stimuli. *Biological Psychology*, 68, 223-235.
- [11] Gross, J. J., & Levenson, R. W. (1995). Emotion Elicitation using Films. *Cognition and Emotion*, 9(1), 87-108.
- [12] Philippot, P. (1993). Inducing and assessing differentiated emotion-feeling states in the laboratory. *Cognition & Emotion*, 7(2), 171-193.
- [13] Russell, A. R., & Mehrabian, A. (1977). Evidence for a Three-Factor Theory of Emotions. *Journal of Research in Personality*, 11, 273-294.
- [14] Staal, J. A., Sacks, A., Matheis, R., Collier, L., Calia, T., Hanif, H., & Kofman, E. S. (2007). The Effects of Snoezelen (Multi-Sensory Behavior Therapy) and psychiatric care on agitation, apathy, and activities of daily living in dementia patients on a short-term geriatric psychiatric inpatient unit. *Int. Journal of Psychiatry in Medicine*, 37(4), 357-370. doi: 10.2190/PM.37.4.a
- [15] Van Diepen, E., Baillon, S. F., Redman, J., Rooke, N., Spencer, D. A., & Prettyman, R. (2002). A Pilot Study of the Physiological and Behavioural Effects of Snoezelen in Dementia. *The British Journal of Occupational Therapy*, 65(2), 61-66.
- [16] Van Weert, J. C., Van Dulmen, A. M., Spreeuwenberg, P. M., Ribbe, M. W., & Bensing, J. M. (2005). Behavioral and mood effects of snoezelen integrated into 24-hour dementia care. *Journal of the American Geriatrics Society*, 53(1), 24-33.
- [17] Westermann, R., Spies, K., Stahl, G., & Hesse, F. (1996). Relative effectiveness and validity of mood induction procedures: A meta-analysis. *European Journal of Social Psychology*, 26, 557-580.



### Appendix: Observation scales

*Attention scale* (6 items,  $\alpha = .795$ )

Items	Value
Head	Passive (0) /active (1)
Eyes	Open (1) / open-closed (.5) / closed (0)
Eyes	Following (1) / blank(0)
Talking	Yes (.5)/ no (0)
Touching	With (1) / without intent (0) /not touching (0)
Attention for application	Yes (1) / no (0)

*Affect scale* (6 items,  $\alpha = .527$ )

Items	Value
Sounds without intent	Positive (1) / neutral (0) /negative (-1) / not (0)
Mouth activity w/o goal	Yes (-1) / no (0)
Hands	Tensed (-1)/ normal (0)
Mouth	Tensed (-1) / normal (0)
Body movement	Rocking (-1) / not rocking (0)
Talking	Positive (1) / neutral (0) / negative (-1) / not (0)

*Arousal scale* (7 items,  $\alpha = .677$ )

Items	Value
Talking	Yes (1) / No (0)
Sounds without intent	Yes (.5) / No (0)
Head	Passive (0) / active (.5)
Head movement	Quick (1) /slow (.5) / not moving (0)
Hand movement	Quick (1) /slow (.5) / not moving (0)
Touching	With (1) / without intent (.5) / not touching (0)
Body movement	Moving (1) / not moving (0)