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DOI: <https://doi.org/10.1016/j.gmhc.2015.10.001>

Other titles: Awakened Art Stories – rediscovering pictures by persons living with dementia utilising timeslips:  
a pilot study

Posted at the Zurich Open Repository and Archive, University of Zurich

ZORA URL: <https://doi.org/10.5167/uzh-119745>

Journal Article

Accepted Version



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Originally published at:

Loizeau, Andrea; Kündig, Yvonne; Oppikofer, Sandra (2016). ‘Awakened Art Stories’ – rediscovering pictures by persons living with dementia utilising timeslips: a pilot study. *Geriatric Mental Health Care*, 3(2):13-20.

DOI: <https://doi.org/10.1016/j.gmhc.2015.10.001>

# **‘Awakened Art Stories’ — Rediscovering Pictures by Persons Living with Dementia Utilizing TimeSlips: A Pilot Study**

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## **Funding Source**

This work was supported by the Center for Gerontology at the University of Zurich. Funding sources are the following: Ernst Göhner Stiftung; Kunsthaus Restaurant; Migros Kulturprozent; Lotteriefonds Kanton Zürich; Katholische Kirche im Kanton Zürich; Alzheimervereinigung Kanton Zürich.

**Declaration of interest** None.

## **Abstract**

*Introduction:* ‘Awakened Art Stories’ is the first creative expression intervention study for persons with dementia (PWD) and their caregivers. The study was conducted at the Kunsthhaus Museum in Switzerland. The intervention utilized TimeSlips to encourage persons living with dementia to create stories about artwork in response to open-ended questions. The aim of this pilot study was to assess the efficacy and feasibility of an intervention through storytelling and a social gathering.

*Materials and method:* A mixed-method pre-post design using semi-structured interviews, written questionnaires, validated and adapted scales, and a self-generated observations’ sheet as well as a visual analogue scale assessed the efficacy as well as the feasibility of the intervention. Participants were four PWDs and their caregivers as well as four volunteers, who supported the PWDs during the sessions. Qualitative data were analysed using thematic analyses and descriptive observations, as well as further feedback from participants, while a Wilcoxon signed-rank test was used to analyse quantitative data.

*Results:* The quantitative findings revealed a statistically significant, positive effect on PWDs’ and caregivers’ mood on the Smiley-Face Assessment Scale directly after the museum session (all participants:  $Z = -4.84, p < 0.001$ ; PWDs:  $Z = -3.57, p < 0.001$ ; Caregivers:  $Z = -3.34, p < 0.001$ ). On the Dementia Attitude Scale, no significant differences in the caregivers’ and volunteers’ attitudes towards dementia were found. No significant differences were found on the Caregiver Burden Inventory either. Although the qualitative findings revealed via thematic analyses that while PWDs attributed their mood to the atmosphere, caregivers attributed it rather to social contacts. All caregivers and most of the volunteers reported a positive change in their attitude towards dementia. In addition, PWDs’ reported that they welcomed the opportunity to contribute and express their thoughts. All participants were highly satisfied with their experience.

*Conclusion:* Despite the small sample size, the many benefits of making art accessible to PWDs and their caregivers, as well as the feasibility of an innovative intervention based on TimeSlips resulted in both quantitative and qualitative evidence.

### **Keywords**

Dementia; Caregiver; TimeSlips; Art; Mood; Attitude

# <sup>1</sup>1. Introduction

Society's understanding of dementia is mainly deficit-oriented. Moreover, the person affected by dementia and their caregivers typically find it hard to accept the illness, and often downplay it instead (Schweizerische Alzheimervereinigung, 2013).

Resource-oriented approaches in dementia are based mainly on a person-centred model, in which all individuals, including persons with dementia (PWDs), are able to live a fulfilled life independently of their health condition (Kitwood, 1997). Kitwood's model integrates the physical and psychosocial needs of PWDs and proposed the existence of five essential needs: consolation, bonding, meaningful occupation, inclusion, and identity (Kitwood, 2008). Meaningful activities for PWDs have to be adequate for adults and capable of being integrated into everyday life; further, they should be fun, provide stimulation, and allow expression of individuality (Wickland and Basting, 2009). These ideas are of course reminiscent of earlier insights from positive psychology such as Maslow's hierarchy of needs, which includes, among others, feelings of belonging, self-respect and – in this context most importantly – the desire to realise one's potential (Maslow, 1943). When providing PWDs with an art based intervention, it is essential to stimulate PWDs and give them an opportunity to experience competence by encouraging them to use their preserved abilities or to discover them (Neubauer and Groote, 2012). Carers are frequently involved in the day to day life of PWDs, and an activity that is interesting to caregivers and PWDs is beneficial to both, and can strengthen their relationship (Mittelman and Epstein, 2009). In addition, such activities provide an opportunity for healthy and unwell individuals to share an experience on the same level, and promote self-identity, sense-making, fun, and enjoyment (Neubauer and Groote, 2012). This suggests that creative expression interventions in a social context could be a sensible means of integrating a PWD's essential needs. In addition, art based activities can provide shared experiences, reduce the negative image of PWDs, soften role attributions (Wickland and Basting, 2009) and provide a feeling of freedom as participants do not need any formal qualifications in order to take part in the discussion (Goulding, 2012).

Several museums and institutions already offer activities and programmes for PWDs and their caregivers (Balzani et al., 2014; Brägger, 2012; Eekelaar et al., 2012; Kaster and Winkler, 2008; MacPherson et al., 2009; Mittelman and Epstein, 2009; Potter, 2012). The 'Meet Me' study at the Museum of Modern Art (MoMA) in New York was one of the first art-viewing interventions that included PWDs as well as caregivers and showed benefits for both PWDs and their caregivers among others through an improvement in PWDs' and caregivers' mood directly following the session (Mittelman and Epstein, 2009). However, adequate scientific evaluation of the efficacy and feasibility of programmes based on the *TimeSlips* method has not been undertaken thus far. The first creative expression intervention study in Switzerland, titled 'Awakened Art Stories' at the Kunsthaus Museum in Zurich, was initiated by the Center for Gerontology at the University of Zurich. It sought to address this gap in research, using art and social interactions to point out the positive aspects of dementia.

## 1.1 *TimeSlips*

The *TimeSlips* method, developed by Anne Basting in 1996, offers an opportunity to express one's spontaneity and creativity (Basting, 2012). It encourages PWDs to create stories in response to open-ended questions while viewing staged photographs. PWDs are able to start a creative process without the pressure and need to recall details about the past (Sullivan et al.,

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<sup>1</sup> Abbreviations: Caregiver Burden Inventory (CBI); Dementia Attitudes Scale - Deutsch (DAS-D); Mini Mental Status Examination (MMSE); persons with dementia (PWDs); Smiley-Face Assessment Scale (SFAS).

2014). This approach is called '*failure free*', because it accepts verbalisation as well as unintelligible noises and gestures as valid responses (George and Houser, 2014). Art and creativity becomes a means of communicating and sharing emotions (Balzani et al., 2014), and neither language difficulties nor memory loss pose any barriers. The interaction between the facilitator, who moderates the storytelling, and a group of PWDs encourages an imaginative process (Oppikofer et al., 2014). The answers are subsequently collected and continuously woven into a story. The final product is the story created by the group of PWDs, who benefits from their role as storytellers.

Originally, *TimeSlips* was implemented with nursing home residents, and focused on both PWDs' quality of life and professional caregivers' quality of care (Fritsch et al., 2009). Fritsch et al. (2009) demonstrated a positive relationship between PWDs' engagement and mood, and the nursing home staff's development of a more positive attitude towards the PWDs. This resulted from '*viewing residents in more positive terms*', as well as more and better interactions with and between residents. Another study using *TimeSlips* highlighted an improvement in medical students' attitude towards PWDs because they were 'surprised' by the PWDs' abilities (George et al., 2011).

### **1.2 Differences between 'Awakened Art Stories' and *TimeSlips***

'Awakened Art Stories' followed the same guidelines as *TimeSlips* with the following exceptions: the activity was located in a museum instead of a nursing home; abstract and realistic paintings were used instead of staged photographs; a group setting included caregivers and volunteers; an additional introduction was given, which consisted of reading the story, that was created in the previous session and a subsequent gathering; and PWDs received a printed version of the session's artwork and story. These changes in the setting of *TimeSlips* were introduced partly due to important findings of the 'Meet Me' study, which emphasised the benefits of art-viewing intervention in an environment that was deemed valuable by both PWDs and caregivers (Mittelman and Epstein, 2009). In the 'Meet Me' study, all participants contributed equally to the art-viewing (Rosenberg, 2009), whereas in this study only PWDs contributed to the storytelling discussion in order for their voice to be valued by avoiding any imbalances due to the caregivers' contributions.

### **1.3 The present study**

This pilot study sought to assess the efficacy and feasibility of the intervention project 'Awakened Art Stories' based on *TimeSlips*. The novelty of this study lies in the combination of the location in a museum, the method used with *TimeSlips*, and the group setting, which included PWDs, caregivers, volunteers, a facilitator, and a transcript writer.

Based on the general feedback of a smaller study received in spring 2013, a positive impact on PWD's and caregivers' moods directly after the intervention was predicted. It was hypothesised that a social-related intervention through art would decrease caregiver burden. With the help of intellectual stimulation within a respectful environment, PWDs and caregivers should be able to express common experiences and emotions. Thus, it was predicted that the encouragement and support would enhance PWDs' competences and resources in terms of preserved or discovered abilities. The focus of the caregivers and volunteers were expected to shift towards the PWDs' preserved or discovered abilities, positively altering their attitude towards PWDs. Lastly, it was hypothesised that all the participants would be satisfied with the content and organisation of the intervention, while the volunteers would view it as an inspiring and positive experience.

## **2. Material and methods**

## 2.1 Participants

The intervention took place in autumn 2013 at the Kunsthau Museum in Zurich, Switzerland. Participants were recruited with the help of the following partners: Alzheimer Association Canton Zurich; the Sanatorium Kilchberg; Kunsthau Zurich; the commune of Horgen; and a nursing home that serves a middle class urban neighbourhood. Additional organisations, general practitioners, and the media were contacted to promote the intervention. A project description was handed out at several locations to assist in participant recruitment. Volunteers were recruited through an existing database of previous participants and supporters of the Center for Gerontology Zurich as well as information events organised by the study's partners. Before the study began, the intervention received ethics approval from the Ethics Commission at the University of Zurich and the Cantonal Ethics Commission Zurich. Participants were given an approved information sheet that described the study and signed a consent form.

The study inclusion criteria for PWDs were an understanding of the German or Swiss German language, willingness to participate in the dyad for at least 4 museum sessions, and the diagnosis reported from the caregiver of any form of dementia. PWDs' cognitive status was graded at baseline by a psychologist using the Mini Mental Status Examination test (MMSE, max. score = 30; Folstein et al., 1975) but was only used as a demographic data. If the PWDs did not have capacity to consent, a caregiver acted as a proxy and provided consent on their behalf. Six PWDs were excluded because they were not able to take part in the intervention at least four times. Four PWDs came from a nursing home accompanied by professional carers. One dyad was excluded as the caregiver's recent relocation to Zurich made her feel too burdened to take part in the entire assessment. One person with Parkinson's disease participated in the intervention but was not included in the analysis as he did not meet the inclusion criteria. There were no selection criteria for caregivers and volunteers. PWDs who were not selected for the evaluation were still welcome to participate and were present for the programme.

Data for the volunteers' results were drawn from two consecutive storytelling interventions in 2013: the pilot intervention in the spring, as well as the intervention in the autumn. Four volunteers took part in both sessions, while one participant took part in the autumn session only. Therefore, we excluded the participant's data from the analysis. The volunteer's role was to support the PWDs by providing encouragement and a resource-oriented atmosphere during the sessions. Each volunteer was responsible for one to two PWDs per museum session.

## 2.2 Intervention

The intervention took place on Tuesday afternoons from 3 to 5 pm over nine weeks. It was divided into two parts: one hour of improvisational storytelling, followed by an hour-long social gathering with refreshments provided for all participants.

### 2.2.1 Storytelling

The first 15 minutes of each session consisted of giving the group of PWDs and their caregivers a warm welcome, reminding them of the timetable for the day as well as the *failure-free* concept of storytelling, and reading the story created at the previous session with the help of its corresponding painting. Participants, accompanied by the caregivers and volunteers, then moved to one of the exhibition rooms, where chairs were arranged in a semicircle in front of a selected piece of artwork. PWDs sat at the front, with caregivers and volunteers behind them. Next to the artwork, a trained and certified TimeSlips facilitator asked PWDs open-ended questions about the painting (e. g. 'Where could that be? Do the persons in the painting know each other?' etc.). Every answer was accepted and transcribed

by another trained and certified *TimeSlips* facilitator and woven into a story. In order to give value to every PWD's answer and to maintain the enthusiasm, the facilitator read each PWD's answer back to the participants twice. During the storytelling, caregivers listened to the PWD's stories, while volunteers acted as prompters, repeating missing information into the PWDs' ear. At the end of the storytelling process the participants created and agreed on the title of the story. Following this first one hour activity, the small groups returned to the initial room.

### *2.2.2 Social gathering*

The informal and leisurely gathering gave all participants the opportunity to interact while enjoying refreshments in a comfortable atmosphere. During this time, the volunteers' role was to encourage social interactions among the PWDs using a long table with chairs to facilitate this. Before leaving, every PWD received a printed version of the current session's artwork and the story they had invented in the previous session.

## **2.3 Design**

The assessment followed a mixed-method pre-/post-test (T1/T2) design. The study focused on two aims: the efficacy of the intervention on the participants and an assessment of the feasibility of the intervention based on *TimeSlips*.

## **2.4 Measures**

The assessment consisted of semi-structured interviews, written questionnaires developed for this study, validated and adapted measurement scales, and field observations. An explorative approach including several variables was chosen to evaluate the study in order to generate a comprehensive foundation for subsequent studies.

### *2.4.1 Pre and post measurements of PWDs and caregivers*

Self-generated, semi-structured interviews of PWDs and caregivers were conducted face to face at the participants' homes two weeks before and after the first and last museum session. In addition to demographic data, interviews collected pre and post information about the impact on the participants and the feasibility of the intervention. Questions included variables such as subjective well-being, preserved or discovered abilities, caregiver burden, social interactions, communication between PWDs and caregivers, attitude towards dementia, satisfaction with the intervention itself and with the interventions' division in two parts, and the expectations regarding the intervention. The participants' answers were transcribed in notes by one researcher. Caregivers completed the following scales at the time of the pre- and post-interview.

*Caregiver Burden Inventory* (CBI; Novak and Guest, 1989) is a 24-item measure, with 5-point Likert scale. This test quantifies burdens in several aspects of a caregiver's life, as well as the influence of patients' and caregivers' characteristics on its different dimensions. Previous assessments of the CBI have found it to be of high internal consistency (Marvardi et al., 2005). The scale was adapted but not validated for this study by translating the English version into German, and only two of five subscales appropriate to this study were used. Caregivers filled out the subscales 'Emotional health' and 'Social relationships' which included 5 items each.

*Dementia Attitudes Scale-Deutsch* (DAS-D; Peng, Moor, and Schelling, 2011), is a validated German translation of the Dementia Attitudes Scale (DAS; O'Connor and McFadden, 2010). This tool has a 20-item 7-point Likert scale with high internal consistency that measures attitudes towards dementia.

#### *2.4.2 Pre and post measurements of volunteers*

Pre- and post-data were collected before the spring session and after the autumn session, respectively. Volunteers completed the DAS-D, closed- and open-ended written questionnaires, which contained a demographic survey and questions regarding the volunteers' satisfaction with the intervention, involvement, and attitude towards dementia.

#### *2.4.3 Museum data-collection*

Immediately before and after each museum session, the PWDs' and caregivers' moods were assessed using the Smiley-Face Assessment Scale (SFAS), which is a self-report visual analogue scale. Its pictorial response system consists of five faces ranging from unhappy to happy. An observation sheet generated for this study was used to observe the PWDs' emotions, body postures, social interactions, and capacity to concentrate during all museum sessions. Unguided qualitative impressions to those variables were gathered observationally. The observation sheet was developed in a nursing home and tested for inter-rater reliability. Each PWD was observed four times and each observer evaluated the same two PWDs.

### **2.5 Data analysis**

Quantitative data were analysed using SPSS® (Version 21.0). Only non-parametric statistics were used as the data were not normally distributed (according to Kolmogorov-Smirnov test). A Wilcoxon signed-rank test was used to compare repeated quantitative measurements regarding mood (SFAS), caregiver burden (CBI), and attitude towards dementia (DAS-D).

Qualitative data were extracted from observations, answers and comments from participants. The variables well-being, preserved or discovered abilities, caregiver burden, attitude towards dementia, and feasibility were analysed using summaries and frequencies. Thematic analyses was used to characterize the participants' moods. Categories were created by one author and tested for consistency by a second author.

## **3. Results**

### **3.1 Sample description**

The study included 4 dyads ( $n = 8$ ) and 4 volunteers. The 4 PWDs' mean age was 75.75 years ( $SD = 5.91$ ) and ranged from 71 to 84 years. The 4 caregivers' mean age was 64.5 years ( $SD = 12.37$ ) and ranged from 46 to 72 years. The 4 volunteers' mean age was 70.5 years ( $SD = 14.39$ ) and ranged from 51 to 85 years.

Three dyads constituted the core group of this evaluation because the participants lived together. Three women were diagnosed with early to middle stages of Alzheimer's disease. The fourth dyad consisted of a man in the middle stages of Alzheimer's disease living in a nursing home and his son. The 4 dyad's participation ranged from 7 to 9 sessions for dyads in the core group, and 4 sessions for the dyad with the father living in a nursing home. All PWDs were from diverse social classes. Co-morbidities included incontinence, diabetes, and joint pain. See Table 1 for detailed demographic information. The 4 volunteers consisted of 3 women and 1 man. All volunteers were trained health professionals.

### **3.2 Quantitative results**

The quantitative findings are presented in the following sections.

#### *3.2.1 Current mood*

The current mood showed positive outcomes, which are presented in Table 2. A Wilcoxon test showed a statistically significant, positive, short-term effect on the participants' moods directly after the museum session on the Smiley-Face Assessment Scale ( $Z = -4.84, p <$

0.001). Findings were still significant when analysing PWDs' ( $Z = -3.57, p < 0.001$ ) and caregivers' ( $Z = -3.34, p < 0.001$ ) mood scores separately. On average all participants left the museum session with a better mood, except for caregiver 4, whose average mood remained the same ( $M = 4$ ; score 4 = 'a bit happy').

### 3.2.2 Caregiver burden

Even though the results indicate a reduction in caregiver burden on the subscale 'Emotional health' ( $M_{diff} = 0.5, SD_{diff} = 1.48$ ), there were no significant differences on the two subscales 'Emotional health' and 'Social relationships' from the Caregiver Burden Inventory.

### 3.2.3 Attitude towards PWD

On the Dementia Attitude Scale, no significant differences in the caregivers' and volunteers' attitudes towards dementia were found.

## 3.3 Qualitative results

The qualitative findings are presented in the following sections.

### 3.3.1 Momentary mood

Thematic analyses showed that while PWDs attributed their mood to the atmosphere, caregivers attributed it to social contacts (See Table 3).

### 3.3.2 Subjective well-being

PWDs and caregivers were asked about their well-being after the intervention. One of four PWDs and two of four caregivers noticed a positive change in their subjective well-being 'Yes, I'm not the only one, there are others (PWD 2).' 'In a certain way it mentally unburdens you (caregiver 2).' 'It has also benefited me. It was good for my well-being (caregiver 3).' The other PWDs did not justify their negative answers. One of the caregivers mentioned that it would be exaggerated to say that his well-being had been reduced. The other one explained that since he maintains a stable work-life balance, this intervention alone could not improve his well-being.

### 3.3.3 Preserved or discovered abilities

The intervention aimed to stimulate the intellect and emotions of the PWDs with the help of its resource-oriented structure. Table 4 presents results for PWDs' and caregivers' opinions regarding the abilities that PWDs discovered during the intervention. All PWDs reported that they welcomed the opportunity to contribute and express their thoughts. Three of four were surprised by their imaginative skills. All caregivers reported seeing their PWD show greater patience during the storytelling. Three of them mentioned that their PWD discovered the ability to concentrate and verbally express his/her thoughts during the intervention.

All caregivers were impressed by the attention their PWDs paid to the facilitator, who moderated the storytelling. Three of four reported that their PWD showed increased engagement during the intervention, and attention to the other participants, as well as increased interest in their social environment.

Regarding the caregivers' own abilities, three of four reported discovering the importance of patience and expressed the desire to be more calm and indulgent as well as to invest more in close relationships. The last caregiver mentioned that he gained a better understanding of his PWD and expanded his knowledge about dementia.

### 3.3.4 Caregiver burden

Caregivers were asked about their ability to deal with their burden after the intervention. Two of four reported a positive change. *'Yes, I can deal with it better. [...] I've now noticed that my patience has improved through the project. There's nothing else left to do, either you give in or you increase your patience (caregiver 2).'* *'Yes, it [the burden] changed. There has been a shift towards patience (caregiver 4).'* The two other caregivers answered 'slightly' and 'neutral' without adding any comments.

### 3.3.5 Attitude towards PWD

Caregivers and volunteers were asked about their attitude towards dementia after the intervention. Seven of eight reported a positive change. As examples, a caregiver and volunteer reported the following: *'[...] I have learnt to see my wife as different from others and to get to know her once again. There are also opportunities through illness - not just darkness (caregiver 3).'* *'I became more attentive to this illness through the PWDs' viewing of the paintings. Witnessing the PWDs' painting discussion made me realise what constitutes a creative story (volunteer 2).'* One volunteer did not observe a change in her attitude toward PWDs, but explained that this was because she lived in a nursing home and was in constant contact with PWDs. She pointed out that she had noticed the PWDs' remaining creative abilities.

### 3.3.6 Feasibility of the intervention

*PWDs' and caregivers' satisfaction with the intervention.* All PWDs and caregivers ( $n = 8$ ) reported high satisfaction with the intervention. They appreciated having a positive experience in an environment that was both accepting and stimulating, thus facilitating positive emotions. The three main reasons for their satisfaction were the familiar atmosphere, the very sensitive facilitator, and the good organisation of the intervention. In addition, the caregivers and PWDs reported the importance of their common participation in the intervention. *'I'm happy that my husband accompanies me. It [the intervention] is like medicine. It's nice that he [caregiver 2] also comes along (PWD 2).'* *'I will always come back and my husband also enjoys it. The people really like coming. I think that also has something to do with the facilitator (PWD 3).'* PWDs and caregivers expressed experiencing an enjoyable afternoon together. The intervention met their expectations and all reported a personal gain. All caregivers would gladly recommend the intervention to others.

*Volunteers' satisfaction with the intervention.* Findings indicated that all volunteers ( $n = 4$ ) were satisfied with their role, the team, organisation of the intervention, and overall positive atmosphere. Regarding their support capacity, they mentioned that the assignment of two PWDs to each volunteer was ideal. Volunteers had no suggestions for improvements and emphasised that the intervention was very well designed without any superfluous aspects. *'I would recommend participating because it is a good experience for both parties [PWDs and caregivers] (volunteer 3).'* All volunteers would like to participate again and would recommend the intervention to others.

*The role of the storytelling facilitator.* All caregivers ( $n = 4$ ) reported that the facilitator was able to successfully stimulate the PWDs. *'I go there, because she [facilitator] is so involved (PWD 3).'* The facilitator also validated all PWDs' suggestions to the story. *'Even when someone said something that's not exactly about it [the painting] he wasn't cut off (caregiver 2).'* Volunteers also emphasised the pleasant and stimulating method of guidance and encouragement.

*Importance of the two activities: storytelling and social gathering.* Findings showed that all caregivers (n = 4) thought the social gathering was necessary. In particular, the interpersonal exchange within a comfortable atmosphere and the development of a community feeling were highlighted. After the intervention, the PWDs and caregivers were asked their opinions regarding the two activities. While three caregivers choose the social gathering, three PWDs assessed the storytelling as the most important part. One PWD mentioned ‘*the storytelling part, because it required fantasy (PWD 3)*’. Two participants expressed that both activities were equally important.

## **4. Discussion**

This is the first creative expression storytelling study in Switzerland based on the *TimeSlips* method for PWDs and their caregivers. Despite the small sample size, individual descriptive analyses indicated positive results concerning the effects on participants and the feasibility of the intervention.

### **4.1 Theoretical contribution to the findings**

#### *4.1.1 Mood and subjective well-being*

One of the central findings of the assessment was the positive outcome concerning PWDs’ and caregivers’ momentary moods, which are consistent with the findings from ‘MeetMe’ at MoMA. Sharing this experience with relatives or with others (Mittelman and Epstein, 2009), as well as experiencing positive feedback in a museum, were mentioned by the PWDs and caregivers as reasons for their good mood. Because social programmes where participants receive attention can improve the participants’ mood, the positive findings presented here should not be overstated.

Although this study was limited in its focus on well-being, the ability to directly question participants with dementia about their subjective well-being, instead of asking their proxy, can be seen as a good indicator of their actual well-being. Individuals with dementia are important informants about their own subjective well-being and should be included in related research (Kaufmann and Engel, 2014).

#### *4.1.2 Preserved or discovered abilities, caregiver burden, and attitude towards dementia*

Qualitative results suggested that there is a relationship between the perception of PWDs’ preserved or discovered abilities, caregiver burden, and the attitude of both PWDs and caregivers towards dementia. During the course of the intervention, PWDs became more aware of their abilities and most of the PWDs expressed having more imagination.

The ability to imagine future events correlates with episodic memory in Alzheimer patients (El Haj et al., 2014) and episodic memory improves in aesthetic responses to visual art (Eekelaar et al., 2012). In the present study, positive effect on PWDs’ subjective imagination abilities was found in three of four PWDs. Therefore it seems reasonable to hypothesize that the *TimeSlips* method could similarly improve episodic memory. Not only did PWDs notice this change in their abilities but caregivers also expressed that their PWDs possessed preserved abilities, which are sometimes hidden in everyday life.

One of the reasons for the change in the attitude of caregivers and volunteers was that they were positively surprised by the PWDs’ abilities. This result is consistent with the study using the *TimeSlips* method, in which medical students felt an improvement in their attitude towards PWDs because they were ‘surprised’ by them (George et al., 2011). The students recognized abilities used by the PWDs that they had not been aware of during their medical studies (Solovey, 2013); similar to how caregivers and volunteers recognized PWDs’ abilities at the Kunsthau Museum.

Knowledge of preserved or discovered abilities could positively influence attitudes toward dementia as well as caregiver burden. Quantitative findings regarding caregiver burden showed a small trend of burden reduction, which is consistent with another art intervention for PWDs and caregivers that expressed the need for a larger-scale study with a control group in order to examine the significance of burden (Camic et al., 2014). Additionally, nursing homes have found that the caring situation seems to be less stressful when PWDs experience their own creative abilities and joy through activities (Neubauer and de Groote, 2012; Wickland and Basting, 2009). Moreover, having a negative attitude or stigma seems to influence the burden. Stigmatisation of families with a person who suffers from Alzheimer's disease has a negative impact on caregiver burden (Werner and Werner, 2012).

#### *4.1.3 Feasibility*

The feasibility of a storytelling creative expression intervention for patients at any dementia stage and with diverse forms of dementia has been demonstrated at several museums and institutions (Balzani et al., 2014; Basting, 2012; Phillips et al., 2010). This person-centred approach (Kitwood, 2008) allows PWDs to be involved in the emergence of the story in different ways and intensities. The central importance of a sensitive facilitator in order to achieve this has been shown in this study and in other museum assessments for PWDs (Brägger, 2012; Mittelman and Epstein, 2009; Potter, 2012). During the storytelling of the present study, realistic and abstract paintings fostered participants' creativity. Paintings might thus have the same benefits of the staged photographs used in *TimeSlips*.

All participants were satisfied with both the content and organisation of the intervention. Additionally, and consistent with our hypothesis, volunteers experienced the intervention as positive and inspiring. The results highlighted the importance not only of the storytelling, but also of the social gathering. It allowed participants to talk to everyone involved, both about their personal situation and about art and living 'normally'. Caregivers especially benefited from conversations during the social gathering, whereas PWDs interacted more during the storytelling. Therefore, it is recommended that this two-part structure be maintained in similar programmes.

Assessing the feasibility affirmed that with the support of the volunteers, a secure and accepting environment can be created in order to allow 'normality'. In contrast to the MoMA study (Mittelman and Epstein, 2009), this study was conducted within the normal opening hours of the museum. It seems that the welcoming environment of the museum where PWDs and caregivers felt valued contributed significantly to the PWDs positive responses (Young et al., 2015). Volunteers and caregivers were of the opinion that the positive impacts of the intervention on the PWDs should be displayed in public. Opening the sessions to guests could be an effective way to create a more positive image of dementia to the wider public. The intervention was carried out without any problems and no negative interactions with other museum visitors were experienced.

#### **4.2 Limitations**

The intervention resulted in short-term positive effects on the participants. Such interventions are appropriate when short-term changes are desired and sufficient (Houser et al., 2014). When working with PWDs, the focus can hardly be on long-term effects regardless of the length and intensity of the intervention (Martin and Schelling, 2005; Stoppe, 2006). Regarding the trends in the variables 'caregiver burden' and 'attitude towards dementia', a larger sample with a control group would be necessary to assess their potential significance in the population. As it is with other studies in this field (Young et al., 2015), the sample size of this study was rather too small for the study purpose and thus the findings are considered with

prudence. Furthermore, the relationship between the variables might have been under- or overestimated, due to the use of only two subscales of the CBI and the adaptation of the DAS-D terms. A more robust instrument might have been useful to improve field observations based on subjective evaluation. Confounding variables such as the progression of dementia may have influenced the results of this study. Post-intervention measures might have been insightful in this regard.

#### **4.3 Research implications**

Future research should continue to explore the link between caregiver burden, attitude towards dementia, and PWDs' preserved or discovered abilities, and should look at possible attitude changes towards dementia on a more societal level. Moreover, a *TimeSlips*-based approach could be used to investigate other variables relating to emotions, concentration, creativity, or social interactions. This could be done using audio or video analysis. Other authors who have assessed the process of viewing and making art have also suggested using electronic means (Camic et al., 2014; Eekelaar et al., 2012). Future research should explore the humane approach of asking PWDs directly about their emotions or subjective well-being, as their answers are valuable. *TimeSlips* interventions should use the Over Agitation Severity Scale (Yudofsky et al., 1997), since an evaluation based on the Analytical Hierarchy Process (AHP) indicates it to be the optimal scale for rating anxiety or agitation in PWDs when using *TimeSlips* (Sullivan et al., 2015).

Due to the degenerative aspect of dementia, art based interventions should continue to focus on 'the moment', assessing the variables of interest immediately before and after the intervention in order to avoid losing valuable results. Similar to a caregiver's statement at the National Gallery of Australia '*You do it for the moment*' (MacPherson et al., 2009), a caregiver at the Kunsthaus Museum expressed the following: '*Everything becomes unimportant when in front of the painting. Whilst participating in the session you're transported away from your daily routine - only the moment is important (caregiver 3)*'. In general, randomised controlled trials with an immediate post intervention report should be used to increase the validity of this line of research. As previously reported in a review about the impact of art based interventions on cognition in PWDs, further studies should examine interactions with the various stages of dementia (Young et al., 2015) in order to determine the best design for the respective stages.

Further interventions based on *TimeSlips* could assess more long-term effects such as potential improvements in dyadic communication resulting, for example, from the story which the participants take home. The story as a final product represents a shared positive experience. Even if the PWD does not remember this experience, his/her caregiver can have a neutral conversation with him/her, which is not about care or everyday life topics. The caregiver can recall the contribution of his/her PWD during the storytelling. The possibility of using the stories in order to reduce the deficit-oriented image of dementia in non-participants could also be assessed. Ideally, the larger public could be inspired to reconsider this negative image based on real experiences.

Future interventions should continue to involve PWDs and their caregivers, also illustrated in other related studies (Mittelman and Epstein, 2009), the results demonstrated benefits for both parties, which were partially due to their interactions and the shared experience.

#### **4.4 Clinical implications**

This study implies that multiple session museum programmes address shared joyful and meaningful experiences of formal and informal caregivers together with PWDs. As such participating in a creative storytelling programme at a museum enhances not only mood,

concentration and communication skills with PWDs, it also increases positive affect and patience in caregivers and an enhancement of positive interactions of caregiver-patient dyads. Resources crucially needed for the empowerment and enablement of caregivers, as well as for the feeling of self-efficacy and satisfaction of the PWDs. Finally, the findings of this study indicate that interventions based on *TimeSlips* might provide a cost effective means of therapy outside of the clinical setting.

## **5. Conclusions**

It is the first study having evaluated the *TimeSlips* Method in a museum context taking into account three groups of persons: persons living with dementia, caregivers and thirdly volunteers. The study illustrated the positive effects and feasibility of an intervention based on *TimeSlips* and the subsequent necessity to continue the development of creative expression and storytelling. This intervention resulted in a positive impact on mood and potentially on well-being, on preserved or discovered abilities, caregiver burden, and attitude towards dementia. It allowed the PWDs to experience life-enriching moments, and offered a means of normal participation and integration in public life. Inventing stories can thus be deemed a worthwhile and meaningful activity for PWDs and their caregivers. Therefore, this study provides useful indications for further studies in this field.

Having presented the result of this study on Alzheimer Congresses, the very great interest in it encourages us, to provide these results to a larger group of professionals. Since the first use of this kind of intervention in Switzerland, 49 creative storytelling sessions have taken place at the Kunsthhaus Zurich and Aargau, the Foundation Beyeler in Riehen, the Kirchner Museum in Davos, and at the Zentrum Paul Klee in Bern.

### **Acknowledgements**

We would like to thank the team of the Center for Gerontology for the organisation of the intervention. Likewise we acknowledge the Kunsthhaus Museum for the generous collaboration. We thank Professor Mike Martin of the University of Zurich and Professor Karin Wilkening for their theoretical advice, as well as Professor Martin Orrell and Dr Emese Csipke of University College London for commenting and advising on this article.

Finally, we would like to acknowledge the invaluable contributions of all participants, who took part in this study for their time and commitment. This study formed Yvonne Kündig's and Andrea Loizeau's master thesis for the University of Zurich.

## References

- Balzani I, Bucci C, Bellola LC, Mei M. A più voci – with many voices. The Palazzo Strozzi project for people with Alzheimer’s and their caregivers. In: Nardi E, Angelini C, editors. *Best Practice 3: A tool to improve museum education internationally*. Rome: Edizioni Nuova Cultura; 2014. p. 205–14.
- Basting AD. *Das Vergessen vergessen: Besser leben mit demenz* (G. Kreuzner, trans.). 1st ed. Bern: Verlag Hans Huber; 2012.
- Brägger M. "Pilotprojekt Naturmuseum für alte Menschen": Begleitstudie. Winterthur: Naturmuseum Winterthur; 2012.
- Camic PM, Tischler V, Pearman CH. Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers. *Aging Ment Health* 2014;18:161–8.
- Eekelaar C, Camic PM, Springham N. Art galleries, episodic memory and verbal fluency in dementia: An exploratory study. *Psychology of Aesthetics, Creativity and the Arts* 2012;6:262–72.
- El Haj M, Antoine P, Kapogiannis D. Similarity between remembering the past and imagining the future in Alzheimer’s disease : Implication of episodic memory. *Neuropsychologia* 2014;66: 119–25.
- Folstein MF, Folstein SE, McHugh PR. “Mini-mental state”: A practical method for grading the cognitive state of patients for the clinician. *J Psychiat Res* 1975;12:189–98.
- Fritsch T, Kwak J, Grant S, Lang J, Montgomery RR, Basting AD. Impact of TimeSlips, a creative expression intervention program, on nursing home residents with dementia and their caregivers. *Gerontologist* 2009;49:117–27.
- George DR, Houser WS. “I’m a storyteller!”: exploring the benefits of TimeSlips creative expression program at a nursing home. *Am J of Alzheimers Dis Other Demen* 2014;29:678–84.
- George DR, Stuckey HL, Dillon CF, Whitehead MM. Impact of participation in TimeSlips, a creative group-based storytelling program, on medical student attitudes toward persons with dementia: a qualitative study. *Gerontologist* 2011;51:699–703.
- Goulding A. Lifelong learning for people aged 64 within the contemporary art gallery context. *Educational Gerontology* 2012;38:215–27.
- Houser WS, George DR, Chinchilli VM. Impact of TimeSlips creative expression program on behavioral symptoms and psychotropic medication use in persons with dementia in long-term care: a cluster-randomized pilot study. *Am J Geriatr Psychiatry* 2014;22:337–40.
- Kaster S, Winkler F. Emotionen gegen das Vergessen. Menschen mit Demenz erleben Kunst im Museum. *Standbein Spielbein. Museumspädagogik aktuell, ALTERnativen im Museum - Vermittlung für und mit Senioren* 2008;82:32–37.
- Kaufmann EG, Engel SA. Dementia and well-being: A conceptual framework based on Tom Kitwood’s model of needs. *Dementia* 2014 Jun 19 [Epub ahead of print].
- Kitwood T. *Demenz. Der person-zentrierte ansatz im umgang mt verwirrten menschen*. 5th ed. Bern: Huber; 2008.
- Kitwood T. The experience of dementia. *Aging Ment Health* 1997;1:13–v22.
- MacPherson S, Bird M, Anderson K, Davis T, Blair A. An Art Gallery Access Programme for people with dementia: ‘You do it for the moment’. *Ageing & Mental Health* 2009;13:744–52.
- Martin M, Schelling HR. *Demenz in schlüsselbegriffen. Grundlagen und praxis für praktiker, betroffene und deren angehörige*. 1st ed. Bern: Verlag Hans Huber; 2005.

- Marvardi M, Mattioli P, Spazzafumo L, Mastriforti R, Rinaldi P, Polidori MC, et. al. Study Group on Brain Aging, Italian Society of Gerontology and Geriatrics. The Caregiver Burden Inventory in evaluating the burden of caregivers of elderly demented patients: results from a multicenter study. *Aging Clin Exp Res* 2005;17:46–53.
- Maslow, AH. A theory of human motivation. *Psychological review* 1943;50: 370–396.
- Mittelman MS, Epstein C. Research: MeetMe at MoMA program [Internet]. The Museum of Modern Art MoMA Alzheimer's Project; 2009 [cited 30 May 2013]. Available from [http://www.moma.org/momaorg/shared/pdfs/docs/meetme/Resources\\_NYU\\_Evaluation.pdf](http://www.moma.org/momaorg/shared/pdfs/docs/meetme/Resources_NYU_Evaluation.pdf).
- Neubauer F, de Groote K. *Auf Flügeln der kunst: Ein handbuch zur künstlerisch-kulturellen praxis mit menschen mit demenz*. München: Institut für Bildung und Kultur; 2012.
- Novak M, Guest C. Application of a multidimensional caregiver burden inventory. *Gerontologist* 1989;29:798–803.
- O'Connor ML, McFadden SH. Development and psychometric validation of the Dementia Attitudes Scale. *Int J Alzheimers Dis* 2010;2010:1–10.
- Oppikofer S, Wilkening K, Angst Fuchs S. Opgewekte kunstverhalen. In : van Hoof E, Wouters EJM, editors. *Het verpleeghuis van de toekomst is (een) thuis*. Houten: Bohn Stafleu van Loghum; 2014. p. 31–34.
- Peng A, Moor C, Schelling HR. Einstellungen zu Demenz: Uebersetzung und Validierung eines Instruments zur Messung von Einstellungen gegenüber Demenz und demenzkranken Menschen (Teilprojekt 1). *Zürcher Schriften zur Gerontologie* 6/2008. Zürich: Zentrum für Gerontologie der Universität Zürich; 2011.
- Phillips LJ, Reid-Arndt SA, Pak Y. Effects of a creative expression intervention on emotions, communication, and quality of life in persons with dementia. *Nurs Res* 2010;59:417–25.
- Potter S. InMind at the RA 2011: Evaluation Report [Internet]. The Royal Academy of Arts; 2012 [cited 16 Apr 2014]. Available from <http://static.royalacademy.org.uk/files/in-mind-atthe-ra-evaluation-report-final-1272.pdf>.
- Rosenberg F. The MoMA Alzheimer's project: Programming and resources for making art accessible to people with Alzheimer's disease and their caregivers. *Arts & Health: An International Journal for Research, Policy and Practice* 2009;1:93–97.
- Schweizerische Alzheimervereinigung [Internet]. Zahlen und Fakten zur Demenz. Yverdon-les-Bains: Schweizerische Alzheimervereinigung; 2013. [cited 2 Dec 2014]. Available from: <http://www.alz.ch/index.php/zahlen-zur-demenz.html>.
- Solovey, M. Storytelling program helps change medical students' perspectives on dementia. *Penn State News*. 2013 Jun 18. Available from: <http://www.sciencedaily.com/releases/2013/06/130618113846.htm>
- Stoppe G. *Demenz: Diagnostik - Beratung - Therapie*. München: Ernst Reinhardt Verlag; 2006.
- Sullivan EL, Sillup GP, Klimberg RK. Timeslips—Comparing agitation and anxiety rating scales to evaluate the benefit of non-pharmacologic creative sessions in nursing home patients with dementia. *Open J Nurs* 2014;4:451–64.
- Sullivan EL, Sillup GP, Klimberg RK. Using the analytical hierarchical process to determine the optimal scale to assess people with dementia pre and post timeslips sessions. *Emerald Group Publishing Limited* 2015;17:127–47.
- Werner P, Mittelman MS, Goldstein D, Heinik J. Family stigma and caregiver burden in Alzheimer's disease. *Gerontologist* 2012;52:89–97.
- Wickland A, Basting, A, editors. 2009 Next Steps Think Tank: How can we radically transform activities in long term care? [Internet]. University of Wisconsin Madison

- Center on Age & Community; 2009 [cited 7 Apr 2014]. Available from:  
[http://www.pioneernetwork.net/Data/Documents/2009\\_Next\\_Steps\\_Think\\_Tank.pdf](http://www.pioneernetwork.net/Data/Documents/2009_Next_Steps_Think_Tank.pdf).
- Young R, Camic PM, Tischler V. The impact of community-based arts and health interventions on cognition in people with dementia: a systematic literature review. *Aging & Mental Health* 2015;ahead-of-print: 1–15.
- Yudofsky SC, Kopecky HJ, Kunik M, Silver JM, Endicott J. The Overt Agitation Severity Scale for the objective rating of agitation. *The Journal of Neuropsychiatry and Clinical Neurosciences* 1997;9: 541–48.

## Tables

**Table 1**  
Demographic information.

PWD ( <i>n</i> = 4)	1	2	3	4
Age (years)	76	71	72	84
Gender	Female	Female	Female	Male
Education (years)	10 years	9 years	9 years	10 years
Stage of dementia	Early	Middle	Early	Middle
MMSE	24	17	21	Unknown <sup>a</sup>
Experience with art	Photography	None	Museum visitor, music	Museum visitor
Place of residence	Home	Home	Home	Nursing home

<sup>a</sup> not assessed via MMSE, middle stage according to caregiver.

**Table 2**  
Comparison of measures on the SFAS assessing  
PWDs' (*N* = 4) and caregivers' (*N* = 4) moods  
directly before and after each museum session.

	<i>n</i> <sup>a</sup>	<i>M</i> ( <i>SD</i> )	<i>Md</i>	Wilcoxon <i>Z</i> , <i>P</i> (Sig)
PWD				
PRE	28	4.04 (0.92)	4	
POST	28	4.75 (0.44)	5	- 3.57, 0.00***
<i>df</i>		2		
Caregiver				
PRE	28	3.57 (0.92)	4	
POST	28	4.36 (0.49)	5	- 3.34, 0.00***
<i>df</i>		2		
All participants				
PRE	56	3.80 (0.94)	4	
POST	56	4.55 (0.50)	5	- 4.84, 0.00***
<i>df</i>		2		

*n*<sup>a</sup> = number of measurements over the sessions; *df*  
= degrees of freedom; \*\*\**p* < 0.001; *M* = mean;  
*SD* = standard deviation; *Md* = median.

**Table 3**

Mood attribution categories with related frequencies and example quotations drawn from the thematic analysis.

Categories	Frequencies	
	PWD ( <i>n</i> = 4)	Caregiver ( <i>n</i> = 4)
Social contacts <i>'You feel the contact' (PWD 3). 'I have spoken to many people, the need is there' (caregiver 3).</i>	8	29
Atmosphere <i>'I feel welcome and that makes me happy' (PWD 2). 'It's becoming more fun' (caregiver 1).</i>	20	10
Resources <i>'It's interesting' (PWD 1). 'My wife participated. She surprised me by the way that she grasped the story.' (caregiver 2).</i>	13	28
Other events <i>'I used to be angry, but not in connection with here' (caregiver 1).</i>	0	8

**Table 4**

PWDs and caregivers reports about PWD's preserved or discovered abilities due to the intervention.

	Number mentioned aspects <sup>a</sup>	
	PWD ( <i>n</i> = 4)	Caregiver ( <i>n</i> = 4)
Patience	2	4
Ability to contribute	4	3
Concentration	0	3
Verbal abilities	4	2
Humor	1	2
Fantasy	3	1

<sup>a</sup> max. = 4, min. = 0.