Visiting the museum together: Evaluating a programme at Auckland Museum for people living with dementia and their carers

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Museums have an increasingly important role in supporting specialized groups including people with dementia. This practice-based report discusses the development, delivery and evaluation of a six-week programme for people living with dementia and their carers at Auckland Museum in 2014. The programme, delivered by specialist volunteers, was evaluated through observation during museum-based sessions followed by focus groups and interviews. Overall, the programme expanded the community opportunities available for people with dementia and their carers, and was considered a success in terms of socialization and through providing a positive and shared experience. Evaluation highlighted programme improvements for future iterations.

**Keywords:** dementia; shared experiences; museums; volunteers

Introduction

Dementia is a degenerative disorder that affects memory and other cognitive processes including language (Alzheimers Association, 2014). In 2011 in New Zealand, there were just over 48,000 people living with dementia and, given the projected increase in numbers of older people, the number of people living with dementia is expected to almost double by 2026 (Ministry of Health, 2013). Dementia has a considerable impact on the person’s well-being as well as his/her social environment (Goldsteen et al., 2007). Consequently, the services provided to people with dementia and their families (usually informal carers) are crucial to the well-being of both. It has long been known that in order to meet the needs of people with dementia effectively, their informal carers, for example, wives, husbands, daughters and sons, should be supported alongside the person they care for (Jorgensen, Parsons, & Jacobs, 2009).

Providing normalized activities for people with dementia and their carers and building on their strengths have far greater benefits than simply offering respite care (Mittelman, Roth, Coon, & Haley, 2004). Many community programmes have been developed beyond medical models of care and intervention, which give respite to the carers as well as pleasure and assistance to the person with cognitive impairments (Camic, Tischler, & Pearman, 2014; Flatt et al., 2014).

Museums and art galleries are engaging with this issue. More than just cultural treasure houses, museums are places of social engagement, well-being and learning (Camic et al., 2014). They have a responsibility to address social exclusion and increase the diversity of...
audiences, and many now offer specialized programmes for different populations (Camic & Chatterjee, 2013). Museums can decrease stigma associated with dementia, model social inclusiveness and improve quality of life (Ander et al., 2011). Gallery-based art viewing and practical art-based activities have achieved benefits for people with dementia (e.g. Rhoads, 2009). Other museums have taken handling collections to older adults living in residential care (e.g. Thomson & Chatterjee, 2014) or used reminiscence therapy (e.g. House of Memories, 2015).

Rhoads (2009) has observed that expanding the lived worlds and opening up spaces often difficult for people with dementia, such as museums, have the benefits of increasing opportunities for socialization, engagement, creativity and enjoyment for both carer and the person with dementia. This concept led to Auckland Museum, a large multi-disciplinary museum, piloting and evaluating a programme for people with dementia and their carers. The project included opportunities to handle objects, view images and visit galleries.

Methods
The programme, a partnership between Auckland Museum, Alzheimers Auckland, the local organization for the New Zealand Alzheimers Association, and the University of Auckland, was developed collaboratively in consultation with all the partners and evaluated by Auckland Museum. The main goal was to examine the experience of a six-week programme for people with dementia and their carers delivered at Auckland Museum by specialist volunteers in conjunction with an Alzheimers Auckland fieldworker. Each of the partners had specific goals and the Auckland Museum’s aims were to identify the most appropriate delivery mechanisms, ascertain the satisfaction levels of carers and specialist volunteers, and consider the most appropriate way to run future programmes for people with dementia.

Programme
The programme (Table 1) offered two hourly sessions, held in afternoons over six weeks. Each session was led by a specialist volunteer, supported by a second volunteer. The volunteers were recruited from the pool of Auckland Museum volunteer guides and developed their own sessions within the parameters of the project. The volunteers received training from Alzheimers Auckland in order to enhance their understanding of dementia. Alzheimers Auckland recruited participants, attended each session and supported all participants.

Participants were met each week and accompanied to a secure, self-contained suite of rooms with kitchenette and disabled toilet facilities, the Members’ Lounge. Sessions

Table 1. Museum programme outline.

| Programme outline |
|-------------------|
| 1. Based wholly in Members’ Lounge using objects related to dinosaurs and fossils |
| 2. Tour of the Origins Gallery |
| 3. Based wholly in the Members’ Lounge discussing Ancient Egypt using objects and images |
| 4. Based wholly in the Members’ Lounge looking at historic images of Auckland |
| 5. Tour of the Wild Child Gallery (toys and school related objects) with movable seating |
| 6. Tour of the Scars on the Heart Gallery (World War II) |
began with a settling-in period of 20–30 minutes, followed by the session content delivered over 35–40 minutes including time moving to and from galleries. Every session finished with refreshments and a chance for socialization. Participants could leave when it suited them.

**Participants**

Alzheimers Auckland invited a group of eight people with dementia and their carers to join the programme. These participants were considered to have an interest in history and/or the museum and their stage of dementia would allow them to cope with the programme. Participant data (using pseudonyms) are summarized in Table 2. The average age of the participants with dementia was 81 years (three men, five women). There were seven carers who attended regularly (three males, four females, two children, five spouses).

**Ethics**

As this was a programme with planned evaluation, consent to participate in the project was sought from all participants including the people with dementia, their carers and the specialist volunteers. Conducting research with people who have cognitive decline can be difficult due to potential problems in seeking informed consent (Cubit, 2010). Living with dementia does not mean a person is automatically unable to consent; in the mild to moderate stages, people with dementia are capable of expressing their desire to engage in research and discuss consent (Cubit, 2010). Where the potential participant lacks this capacity, then the person responsible or carer may be approached for consent (Cubit, 2010), since they will have an enduring power of attorney. Approval by proxy (usually the next of kin) can be problematic as their own personal views may override that of their relative; however, approval by proxy remains a common practice (Cubit, 2010; Higgins, 2013). For this project, all participants were, however, able to provide their own written consent. The University of Auckland Human Participants Ethics Committee granted ethics approval for the project in July 2014 (Reference Number 012068).

**Project evaluation**

For the purpose of evaluation, quantitative and qualitative data were collected. An independent health researcher (IHR) conducted non-participant observation of the people with dementia (time-sampling and continuous observation) for all sessions. Time-sampling was used while the themed content was being delivered (approximately 40 minutes) with continuous non-participant observation during the rest of the session, focusing on socialization and group dynamics for all participants. The time-sampling data were collected using a pragmatic scoring system based on a seven-point Likert style response designed to evaluate the attentiveness of the people with dementia over one-minute periods (see Table 3). The scale was developed by Professor Matthew Parsons, University of Auckland, to assess attentiveness during an activity in people with dementia. While the scale has to date not been validated, it had the advantage of allowing for a large number of data points to be collected together with observations to focus on the participants in equal measures. Strong correlations have been found between time-sampling, observational data and continuous observational data (Cohen-Mansfield & Libin, 2004; Parsons, 1991); however, in this project the IHR found it difficult to observe whether the person with dementia was genuinely engaged or interested in the session.
Table 2. Participant demographics.

| Name (PLWD) | Age | Symptomatic (date of diagnosis if known) | Diagnosis | Sessions attended | Carer (C) | Age group (years) | # Years as carer |
|-------------|-----|------------------------------------------|-----------|------------------|-----------|------------------|-----------------|
| Elizabeth   | 79  | 5–6 years                                | AD        | 1–6              | John (husband) | 55 +             | 5–9             |
| Rebecca     | 75  | 4 years                                  | AD        | 1–6              | Tracey (daughter) & Stewart (husband) | 35–44             | <1              |
| Isla        | 87  | 4 years                                  | AD        | 1–6              | Amy (daughter) | 55 +             | 1–4             |
| Michael     | 83  | 4 years (January 2010)                   | AD & vascular dementia | 2–6 | Jenny (wife) | 55 +             | 1–4             |
| Liam        | 90  | 3 years (January 2013)                   | Multi-infarct/vascular dementia | 2–6 | Robert (son) | 35-44             | 1–4             |
| William     | 73  | 5–6 years (3–4 years)                    | AD        | 2–6              | Diana (wife) | 55 +             | <1              |
| Daisy       | 87  | 4–5 years (September 2012)               | AD        | 1–2              | Glenda (daughter) | DNC             | DNC             |
| Stella      | 74  | About 1 year                             | AD        | 1                | DNC       | DNC              | DNC             |

Note: AD, Alzheimer’s dementia; PLWD, person living with dementia; C, carer; DNC, data not collected.
At the completion of the programme, two focus groups were held with the carers and one with the specialist volunteers. The focus groups for the carers were conducted at a local church and a café and ran for approximately 90 minutes. The volunteer focus group was held in the museum and ran for about one hour. One-on-one interviews were conducted with the Alzheimers Auckland staff representative and the museum staff involved in organising the programme. Questions elicited responses covering satisfaction with the different sessions, perceived successes and suggestions for improvements. The focus groups were all audio-recorded, transcribed and analysed using a general inductive method of enquiry with themes developed in an iterative fashion. Key themes were identified and coded based on Braun and Clarke’s (2006) thematic analysis. Repeated readings of the transcripts identified initial codes and themes. Themes were then grouped together looking for patterns, variability and consistency. There was consultation within the collaborators as well as reference to literature, and at this stage the themes were rechecked against the transcripts. The transcripts were then coded and examined for commonalities and differences across the themes. Feedback sessions were offered to the specialist volunteers, Alzheimers Auckland and museum staff and notes taken at these sessions were also compared against the themes to ensure consistency.

Results

Attentiveness

Analysis of the time-sampling observation data revealed that overall the attentiveness of the persons with dementia remained consistently high on average, staying at four (focusing on the presenter for 50% of the time) or higher across each of the sessions (Table 4). Session 3 had the highest attentiveness score. This session, delivered wholly in the Members’ Lounge, included objects and images from Ancient Egypt. All the sessions

Table 3. Attentiveness scale.

|   |   |
|---|---|
| 1 | Asleep |
| 2 | Falling asleep, eyes not focused |
| 3 | Distracted, chatting (not on topic) for full minute |
| 4 | Attending speaker (or topic) for less than 50% of the time (not talking) |
| 5 | Attending speaker (or topic) for more than 50% of the time |
| 6 | Attending, focusing on speaker, topic for complete minute |
| 7 | Attending, focused, fully engaged and asking questions |

Table 4. Average attentiveness scores for the people living with dementia (PLWD) for and across the sessions.

| PLWD    | Session 1 | Session 2 | Session 3 | Session 4 | Session 5 | Session 6 | Mean |
|---------|-----------|-----------|-----------|-----------|-----------|-----------|------|
| Michael | 0         | 3.67      | 4.20      | 4.43      | 4.60      | 5.17      | 4.41 |
| Liam    | 0         | 4.50      | 5.70      | 3.86      | 4.00      | 4.67      | 4.54 |
| William | 0         | 5.33      | 6.20      | 5.71      | 6.00      | 5.50      | 5.75 |
| Elizabeth | 5.00    | 5.17      | 4.50      | 5.43      | 4.80      | 4.33      | 4.87 |
| Rebecca | 5.56      | 5.50      | 6.20      | 4.67      | 6.00      | 4.67      | 5.43 |
| Isla    | 6.00      | 5.17      | 6.00      | 6.00      | 4.60      | 5.17      | 5.49 |
| Daisy   | 4.22      | 4.83      | 0         | 0         | 0         | 0         | 4.53 |
| Stella  | 5.11      | 0         | 0         | 0         | 0         | 0         | 5.11 |
| Mean across the session | 5.18 | 4.88 | 5.47 | 5.02 | 5.00 | 4.92 | 5.02 |
based in the lounge had higher mean attentiveness scores than the sessions involving gallery tours. This may have been due to the difficulty observing the participants within the galleries. For example, it would take 10 seconds of the minute’s observation to identify the participant during a gallery session. There were no instances of agitation by the people with dementia, but there were times when several of them started to fall asleep in the sessions within the lounge.

**Focus groups**

Four themes emerged from the detailed analysis of the focus groups and interviews: socialization, programme delivery, shared experiences and practical issues. These themes are summarized in Table 5.

**Socialization**

A key success for this programme was socialization opportunities for people living with dementia and their carers. The Alzheimers Auckland staff member commented: “*This was considered an enjoyable experience by the participants. . . . They especially enjoyed being made so welcome and the engaging styles*. This was echoed by a carer: “*You could see she [Mum] was happy, she enjoyed herself and that is a big thing*” – Tracey (carer C).

This programme provided a “normalized” place for the carers to take the person with dementia. “*The visits were well organized, enjoyable and where you could relax a little, knowing my wife was being in the company of people who understood her condition*” – Stewart (C). This was especially important for the carers, particularly during the winter months. For Robert (C): “*there needs to be more places than the mall, the doctor and the supermarket to go to.*”

| Themes          | Definition                                      | Sub-themes                                      |
|-----------------|-------------------------------------------------|------------------------------------------------|
| Socialization   | Opportunity for both carer and person with dementia to engage with others | Connecting with others                          |
| Programme delivery | Aspects that are important when delivering to people with dementia and their carers | Novelty                                      |
|                 |                                                 | Re-engagement with the Museum                   |
|                 |                                                 | Opening up another venue to visit               |
|                 |                                                 | Group size                                     |
|                 |                                                 | Combining images, objects and galleries         |
|                 |                                                 | Timing and content                             |
|                 |                                                 | Communication                                  |
|                 |                                                 | Engagement                                     |
|                 |                                                 | Presentation style                             |
| Shared experiences | Ability to inspire memories and share experiences | Shared positive experience                     |
|                 |                                                 | Nostalgia                                      |
|                 |                                                 | Memories inspired by the sessions              |
| Practical issues | Planning, resourcing and organizational issues  | Other memories                                 |
|                 |                                                 | Training                                       |
|                 |                                                 | Staffing                                       |
|                 |                                                 | Resources                                      |
|                 |                                                 | Secure space                                   |
|                 |                                                 | Mobility                                       |
|                 |                                                 | Galleries that can be used                     |
Programme delivery and content

The session themes were deemed appropriate and interesting; however, some changes to programme delivery were highlighted for future sessions. Objects in isolation proved difficult for the people with dementia for two reasons. First, for attendees of this older generation, the objects relating to dinosaur and fossils remained ‘random things’ without contextualising images. Second, in the session where objects were discussed and passed around the table, the presenter would move onto another object and story while the object was still being passed around. This did not allow the participants time to handle the object and required split attention between object and presenter. This was challenging for all participants, particularly those with dementia. However, carers considered object handling important as museums rarely allow this. “I was there for the first session and that was fantastic, actually having relics to hold and to look at and to hear about” – Tracey (C).

The Auckland history session achieved the highest satisfaction for the carers. This was due to the “then and now” aspect of the presentation (pictures of historic Auckland and current day pictures of the same place) and because of the “take-home” images for this session. These images encouraged further investigation by the carers.

The gallery visit style was a specialized tour with occasional opportunities for participants to speak. The carers, volunteers and the Alzheimers Auckland representative all advocated for more opportunities for the participants to contribute in both galleries and lounge.

I thought … that it would have been good to be a little bit more interactive. And maybe if each lecture had perhaps concentrated on slightly fewer, some of them in particular, slightly fewer topics and the lecturers would have encouraged interaction by asking questions – Jenny (C).

Shared experiences

There was limited evidence of the programme providing for shared experiences at home after the event for the person with dementia and their carer. One carer did report cognitive benefits: “[Mum] seems to be more ‘with it’ than she was before” – Tracey (C). In contrast, John (C) found that his wife [Elizabeth] did not engage with the session material, saying: “I thought there would be other instances where something would trigger a memory but that didn’t seem to happen much.” There were, however, examples of storytelling and reminiscing from the people with dementia. At times, these memories were relevant to the topic under discussion (e.g. discussion of wartime experiences, Egyptian travels) and at other times unrelated (e.g. stories of weddings, occupations and friends). Carers were observed conversing with each other about the museum visits and their current situations as carers, and this was discussed in the focus groups. The carers valued their experience and the opportunity to visit the museum together where both carer and the person they cared for benefited. Amy (C) commented: “I just know that Mum was really looking forward to it, I mean I was five minutes late and she was worried.” Amy went on to say there was also benefit for her: “It gave me something to keep my interest and it was nice, and pleasant, and meeting the staff was just fantastic.”

Practical issues

The practical issues for all the project partners involved were considerable and important to the success of the programme. Having the Members’ Lounge as the base for all sessions was essential, as the quiet, comfortable space with utilities attached was practical, secure
and appreciated. “It was perfect for them, it was inside, it’s safe, it’s sort of warm and it’s easy – to get in there, parking, lift, go, and know what you’re doing. It’s all what it’s about” – Robert (C).

Participants’ mobility, group size, suitable galleries and availability of handling objects were discussed as impacting on the programme’s success. Providing refreshments to conclude each session encouraged socialization and increased opportunities for conversation. Transport to and from the museum and parking had been considered and catered for. Room layout, noisy galleries, seating, use of audio-visual screen for presentations, and having physical objects and copies of images used in the sessions were also important considerations.

Using the galleries as part of the programme proved taxing partly for physical reasons and partly due to group size. The group tended to split into smaller groups, suggesting that future sessions should consider two sub-groups for the gallery visits. Gallery visits did, however, have high levels of satisfaction and are an integral part of the museum experience. The volunteers were considered appropriate and able to deliver the programme. Specialized training from Alzheimers Auckland and support to deliver the sessions were considered essential. The volunteers reported high satisfaction overall and valued extending the scope of their volunteering duties.

Discussion

Through exploring different means of delivery and content, this project was able to show that Auckland Museum could deliver a programme suitable for people with dementia and their carers using trained volunteer guides. The museum’s objects and images plus the overall experience were able to inspire and elicit responses from all participants. The six sessions explored the use of objects in isolation, images alone, and a combination of objects and images plus three different gallery tours. The most effective session for the people with dementia in terms of attentiveness combined objects and images, strongly suggesting that future sessions should include objects and images to maximize engagement. Gallery sessions proved challenging but would remain essential to future programmes. Many of the objects and images used in the sessions related to examples exhibited within galleries and require visits to these displays to maximize opportunities for engagement.

The programme encouraged socialization and offered a safe place for the people living with dementia. Benefits for the carers through being with their partner/family member in an understanding environment, encouraging conversations and being a pleasant place to visit were evident. The project was designed to develop a programme that carers and people with dementia could attend together. It was hoped that the sessions would encourage interactive engagement by using the objects housed in the museum to reconstruct everyday lives (Rhoads, 2009). The carers did engage with the sessions linking them to their own lives and telling stories. There was limited evidence that the people with dementia had memories of the specific content from the sessions; however, they looked forward to the sessions each week, and within the sessions there were examples of storytelling and sharing of moments from their lives. MacPherson, Bird, Anderson, Davis, and Blair (2009) suggest that it is important for people with dementia to have a positive experience, while long-lasting cognitive benefits are not essential for the programme to be considered successful. This programme succeeded in opening up their community to people with dementia and re-engaging both carers and people with dementia with the Museum.
Rhoads (2009) states that museums can benefit from delivering programmes aimed at people with dementia. This project was able to show that running their own sessions allowed the specialist volunteers to explore new ideas, work in different ways, and have repeated contact with ‘visitors’ which in turn encouraged a greater connectivity to the community. This programme has also expanded the community options available to Alzheimers Auckland and potentially dementia support groups around New Zealand.

Conclusion

The project’s aim was to evaluate and develop a model for future use, rather than generalize across carers and people with dementia. In this way, it has contributed to the museum sector by investigating a New Zealand setting; moving beyond social history and art museums into multidisciplinary museums; and offering an innovative approach to ‘respite’ through dedicated museum programmes which include, and focus equally on, the carers (Camic et al., 2014). A revised programme is planned for 2015 and will evaluate redesigned delivery methods involving object handling, images and the galleries in different combinations. A goal for future programmes is for the “take-home” to inspire conversations at home after the session between the carer and the person with dementia. More training will be provided to the specialist volunteers in modes of delivery suitable to both carers and people with dementia. People in the earlier stages of dementia could contribute actively to aspects of the evaluation. Auckland Museum will adopt an inclusive approach to evaluations by involving the people with dementia in focus groups and using the participants and carers more collaboratively throughout the sessions. Evaluation of future programmes will also consider assessing changes in satisfaction, and well-being, requiring mixed methods to capture both subjective and objective data. Ongoing evaluation will inform programme design to maximize engagement with a varied audience (different ages, genders, ethnicities, stages of dementia). There will need to be on-going flexibility and collaboration with all partners and the participants to ensure that ‘Visiting the Museum Together’ remains as positive an experience as possible for all involved.

Disclosure statement

No potential conflict of interest was reported by the authors.

Notes

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