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Valuing Carers: The impact of House of Memories as a museum-led dementia awareness programme for family caregivers

Rafaela Neiva Ganga[1]

Kerry Wilson[1]

[1] Institute of Cultural Capital, Liverpool John Moores University

Abstract:

Objectives: The paper discusses the value of museums in dementia care practice.

Methods: i) quantitative profiling of participants' care responsibilities; ii) standardized measures of subjective wellbeing and care burden; iii) participant observation; iv) and qualitative feedback.

Results: Data show i) increased dementia awareness; ii) improved subjective wellbeing; iii) increased engagement with museums, and iv) improved capacity for critical, reflective, and creative care practice.

Conclusion: The research contributes to scholarly understanding of care practice, training and development, by exploring the relationship between cultural intermediation, emotions and affect, and their value in health and social care.

Keywords:

Dementia; person-centred care; museums

Word count:

7,911

Valuing carers: The impact of House of Memories as a museum-led dementia awareness programme for family caregivers

Introduction

The benefits of taking part in arts and culture for people with dementia (hereafter PWD) and their caregivers (formal and informal) have been the frequent subject of research in recent years (Camic et al, 2015; Rosenberg, 2009). This reflects a growing trend, internationally, in the promotion of arts and culture ‘in the prevention of ill health, promotion of health, and management and treatment of illness across the lifespan’ (Fancourt and Finn, 2019). The UK All-Party Parliamentary Group on Arts, Health and Wellbeing inquiry report *Creative Health*, for example, appeals for arts and cultural activities to be used more extensively in ‘preventative and restorative strategies and [be] fully integrated into health and social care services’ (2017: 22).

House of Memories (hereafter *HoM*) is a dementia awareness programme led by National Museums Liverpool (hereafter NML) in the UK. The original programme, launched in 2012 with funding from the Department of Health, was designed specifically for the health and social care workforce. *HoM* began as a full-day museum-based training intervention combining forum theatre, interactive facilitation, museum tours, reminiscence therapy techniques and museum education activities.

The programme has since been developed and adapted for delivery in different professional environments, with a range of dementia care providers and several national and international partner museums, supported by a package of supplementary, local museums-inspired resources, including most notably the *My House of Memories* app. All resources were co-designed with PWD and their caregivers and are available via a dedicated dementia-friendly website[i]. More than 12,000 carers from health and social care sectors and ancillary public services have now participated in the programme.

Since 2013, successive mixed-method *HoM* evaluation studies (Wilson and Grindrod, 2013; Wilson and Whelan, 2014; 2016) have consistently shown positive impacts upon *formal* caregivers. These include for example improvements in the subjective wellbeing of participating care workers; improved awareness and understanding of dementia and its implications; empathic skills development in person-centred care; and renewed confidence in trying alternative, creative approaches to living well with dementia.

Recognising the need to support *informal* carers, in 2016, NML launched an iteration of the programme dedicated to carers - the *House of Memories Family Caregivers Awareness Day* (hereafter *HoM Family Caregivers*). Using museum collections and resources, the half-day workshop advocates: empathic communication with people living with dementia; enables greater understanding within the care community of a person's history and life experience; empowers carers with information and ideas that they can use daily; each promoting community wellbeing and resilience.

Researchers at the Institute of Cultural Capital evaluated the launch of *HoM Family Caregivers*, led by NML in collaboration with three museum services in England. This paper summarises our mixed-method research approach and selected findings, including participants' increased awareness and knowledge of dementia; improved subjective wellbeing; increased engagement with museums; and improved critical capacity for reflective and creative care practices.

HoM Family Caregivers essentially supports participants to use museum collections and objects to engage in conversations with PWD. This simple principle combines three components proven to be beneficial for improving the lives of PWD and their caregivers: i) reminiscence activities (Lackoi, 2016); ii) escapism provided by engaging in a museum activity (Falk, 2009); and iii) strong ties created or sustained by meaningful social engagement (Kinsey et al, 2019). Drawing upon studies of intermediation, emotion and affect in culture and heritage work (Wetherell, 2012; Highmore, 2017; Smith et al, 2018), the paper presents a framework for understanding the relationship between the museum-based experience of *HoM* and its outcomes relating to the principles and practice of person-centred care, self-care and respite within the informal care community. This potentially adds value to our understanding, in care scholarship, of both the strategic value of cultural interventions in health and social care, alongside museums' (arguably less quantifiable) contingent value as safe and trusted community assets, particularly for carers.

Rationale and research context

In 2015, dementia affected 47 million people worldwide, a figure predicted to increase to 75 million in 2030 and 132 million by 2050. Dementia refers to a variety of diseases that are characterised by a progressive cognitive and overall decline that requires prolonged periods of care. Family members are the primary carers of people living with dementia, experiencing emotional, practical and economic strain (Schulz and Martire, 2004). Furthermore, carers have poor access to additional support and information from formal services, and therefore, can be inadequately prepared to provide care, which impacts negatively on their own mental health (Zwaanswijk et al, 2013).

The hardship of dementia for individuals, families, communities and health care systems is rising globally as the world population ages. Funding cuts, ageing populations, and a prevalence of chronic conditions, such as dementia, are the major challenges to health and social care systems. Frailty increases the risk of adverse consequences, and the possibility of hospital admission and long-term care, which puts pressure on overloaded systems, with floundering transitions between health and social care leading to expensive hospital stays and ‘bed blocking’ (Ranasinghe et al, 2017).

To address this, the World Health Organization (hereafter WHO) Global Action Plan on the Public Health Response to Dementia (2017) prioritises dementia awareness, diagnosis, and care strategies. Equipping carers with appropriate skills via cross-sector collaborations and interventions will be essential to address the WHO Global Action Plan within national health services already under pressure.

A carer is frequently a spouse or adult child of a person with dementia. The effects of being a family carer are commonly associated with high rates of burden[ii], physical and mental illness, and social isolation, as well as financial hardship. In particular, carer depression is the leading health problem (Spector and Tampi, 2005). Furthermore, many are partner carers who are themselves older adults and facing poor health (O’Shaughnessy et al, 2010).

Not surprisingly, carers tend to experience significant burden performing their caring role, associated mainly with difficulty in coping with the condition and behaviour alterations of the person with dementia. The degenerative nature of the condition related to its unpredictable course increases caring challenges (Zwaanswijk et al, 2013). Consequently, people caring for those in the later stages of dementia, for longer hours and with limited support, tend to experience greater impact on their mental health (Sörensen et al, 2006).

Carer burden is an umbrella term to demonstrate the impact of a variety of factors that can be the cause of distress, strain, and stress (Donaldson et al, 1997). Considering George and Gwyther’s (1986) definition of burden, it can be conceptualised as the set of objective and subjective problems that may be experienced by a carer. Objective problems include activities (time and care tasks), facts (effects on physical and psychological health) and events (social, economic, and occupational impacts); subjective problems are related to the attitudes and emotional reactions of carers (guilt, stress, and concerns). Our focus is on the subjective dimensions of care burden and its impact on carers' wellbeing.

Despite the importance of family members as a resource and support mechanism for PWD (Department of Health, 2009) it is not uncommon for carers to be perceived as 'invisible second patients' as their own health and subjective wellbeing tend to be viewed as secondary to the people they care for (Alzheimer's Society, 2016). However, carers' health and wellbeing are critical to the quality of life of care recipients, and are also crucial to a national health care system for an ageing society. Literature in the field has shown that carer burden is a significant forecaster of the need to resort to formal care of PWD (Torti, et al, 2004), potentially translating into substantial costs for national health care systems.

Thus, there is a need to develop strategies to empower and recognise carers as visible and as significant as those they care for, contributing to restoring feelings of self-worth. At the same time, providing support to carers is essential to relieve the negative impacts of caring, and to promote better dementia care and reduce longer-term healthcare expenditure (Schoenmakers et al, 2009; Schulz and Martire, 2004).

The value of museums in dementia care

Within the UK there is growing momentum around arts and cultural commissioning from health and social services, with particular attention to PWD. In this context, reminiscence therapy techniques have become increasingly popular within the museum and heritage field. Much of this provision revolves around the use of museum collections and objects, in the form of memory or reminiscence boxes that can be used both in the museum and in outreach sessions when offered on loan to care providers. According to Lackoi et al

(2016), the second-largest audience for UK museums in terms of health and wellbeing projects is PWD.

Museum collections can be understood as the objectification of collective memory – a narrative of the past and the present told by an assembly of objects. Those objects can be understood collectively, but also inspire personal stories and evoke memories supporting PWD to live a better life through often-retained long-term memories. Sharing those memories can help to preserve or even build social ties between PWD and their carers; hence, museums are ‘natural’ centres for reminiscing. As David Carr (2006: 112) argues, museums as community assets, and museums’ collections can be instrumental in dementia care: ‘There is no more likely place than the museum for the meeting of recorded history and living memory’.

Chatterjee and Noble (2016) argue that museums as ‘observatories on history and culture’ and ‘interactive environments’ are crucial for future wellbeing. Consequently, there is a growing field of research underpinning the museums for health agenda. These studies demonstrate that museum-led dementia care programmes have therapeutic value with positive social and cognitive outcomes for PWD and their carers (Goulding, 2013; Windle et al, 2014; Young et al, 2015). Furthermore, these programmes usually contain a social component, and are rated highly for their cultural value as an essential aspect of creative cultural participation (Secker et al, 2007). Cultural and artistic engagement can lead to a decrease in depression (Musella et al, 2009) and increase in positive feelings such as enthusiasm and enjoyment (MacPhersona et al, 2009). Museums are thus becoming more recognised as essential community assets, particularly in a context of limited pharmacological treatment for dementia.

Research on the value of museum-led activities for *carers* however remains limited. There has been some research into the value of cultural and artistic activities performed jointly by people with dementia and their carers (Camic et al, 2014; McGuigan et al, 2015). Yet, the value of such activities for carers has not been explored at length. Hunt et al (2018) advocate that regular participation in art-making promotes positive identity, and resilience in carers, while offering a temporary respite from caring demands, helping participants to socialise. Pienaar and Reynolds (2015) found that even short-term arts interventions are meaningful and stress-relieving for carers. Carers valued temporary respite and freedom from caring, reporting enhanced self-esteem, social support and resilience. A qualitative study by Lamar and Luke (2016) about three US museums' dementia programmes[iii] reports findings of enjoyment, socialisation, respite, and personhood as the main benefits. Socializing with peer carers has also been identified as one of the most important benefits of museum-led dementia programmes for informal caregivers (Logsdon et al, 2007).

There are good reasons to believe that museum-based dementia programmes can provide a significant contribution to improve the subjective wellbeing of carers. However, there is more to learn about the value of creative activities in enhancing the quality of care practices and their relationship with creative self-care strategies for the care community. As such, there is a gap in multidimensional approaches that in addition to education and training, provide psychological and emotional support to carers, as well as strategies to develop community and professional support systems.

Methods

Study purpose

This paper discusses selected results of the *Crossing Boundaries*[iv] research programme, taking the *HoM Family Caregivers* evaluation as a case study, whereby 64 participating carers were consulted on their i) sociodemographic characterisation; ii) subjective perceptions of wellbeing pre and post-participation; and iii) use of museums and cultural resources in dementia care practices.

Research setting

The *HoM Family Caregivers* under analysis in this paper took place in three regions in England (North, Midlands and South), including Museum of Liverpool (25 November 2016), in collaboration with New Walk Museum and Art Gallery (Leicester, 2 November 2016), Salford Museum and Art Gallery (14 November 2016), and British Museum (London, 1 December 2016). Each *HoM Family Caregivers* session combines:

- a facilitated introduction to dementia through character-based documentary films to help understand the experience of living with dementia and of being a carer;
- dementia-friendly museum activities specific to each setting, mostly using social history collections and objects; and
- the opportunity to experience the *My House of Memories app*.

Participants also receive supplementary materials to take away, including an *Activity Planner* and a *Memory Tree* adapted to each partner museum. Local representatives from the regional Alzheimer's Society and similar organisations support the workshops to provide information on additional local services.

Research design and procedure

[Figure 1 near here]

The research strategy adopted for the *HoM Family Caregivers* programme was consistent with previous *Crossing Boundaries* evaluation studies (Wilson and Grindrod, 2013; Wilson and Whelan, 2014, 2016), each informed by studies on the impact of arts and culture on subjective wellbeing, including studies within the dementia field (Camic et al, 2015; Camic et al, 2014; Brooker, 2007).

The mixed-method pre-post research methodology design[v] (Figure 1) comprises two online surveys – applied eight weeks before and after participating in the *HoM Family Caregivers* sessions to 64 carers who participated in the sessions and opted into the research after written consent was obtained. These included two standardised measures of subjective wellbeing. The first subjective wellbeing evaluation scale used is a 5-item[vi] adaptation of the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) (Warwick Medical School, 2017)[vii]. The second scale is a 12-item[viii] version of the Zarit Burden Interview (ZBI) (Ballesteros et al, 2012) for the Assessment of Dementia Caregivers' Burden, adapted by Ballesteros, et al (2012). On both scales, a Likert scale format of 5 points was followed, whereby respondents were asked to identify the extent to which they agreed with given statements.

Furthermore, a Smiley-face Assessment Scale (a self-report research instrument using a visual response system with five faces ranging from very sad to very happy) was used on-site to measure the participants' emotional state immediately before and after each session (Rosenberg et al, 2009). The authors conducted participant observation over eight sessions (two at each museum), and field notes were taken at each session, relating to: the characteristics of each participating museum, including physical spaces and collections; programme content and delivery; participants' passive and active responses, including for example contribution to facilitated discussions, visible emotional responses, conversations and reactions between participants. Finally, as part of HoM's social media strategy, during coffee breaks, NML's Marketing Department invited delegates to write their thoughts so far on the *HoM Family Caregivers*. These responses were shared with the research team. Due to the rich and thoughtful comments from delegates, we decided to integrate the results of this marketing strategy in the research design[ix].

Data analysis

Descriptive statistics were used for the participants' sociodemographic profiling. Non-parametric statistical tests (Wilcoxon Signed-Rank Test) were to applied ZBI and WEMWBS, and parametric tests (Paired Sample T-test) were applied to the Smiley-face Assessment Scale; the significance level was set at $p \leq 0.05$. Tests of normality (Shapiro-Wilk test) were carried out on three wellbeing measures. ZBI and WEMWBS scores were not normally distributed; therefore, the Wilcoxon signed-rank test was performed, using IBM SPSS Statistics, Version 25.

Qualitative data (participants' comments, and field notes from the session observations) were analysed by two members of the research team independently using grounded theory (in which themes are not specified before the coding) (Burawoy, 2000). The process involved open coding of the material to identify core categories (themes) and the properties of those categories (sub-themes) using QSR International's N'Vivo Version 11[x]. There was a high level of agreement, and disagreements were resolved by consensus discussion amongst the research team (eg. Table 3). Qualitative data are subsequently used to substantiate quantitative data in terms of impact upon the subjective wellbeing of carers and the causal relationship between specific museums-based components of the programme and the experience of taking part.

Results

Participants' characterisation

[Table 1 near here].

Table 1 demonstrates the baseline sociodemographic and caring profile of the survey respondents, who, according to Archbold (1981) are generally defined as 'care managers', that being adult children or other relatives, providing care alongside other responsibilities and with the support of additional services and interventions. The majority of carers were white (71.88%); married (45.31%); women (76.56%); 50 or more years old (70%); taking care of their parents or parents-in-law (43.75%); not cohabitating with the PWD (68.75%); caring for someone with a moderate (42.19%) stage of dementia, for an average of 3.09 years, and spending on average 11.91 hours a week on domestic care. Half of the carers (50.00%) were employed elsewhere, and more than half declared that they had enough money to live (54.69%).

Levels of satisfaction and engagement

[Figure 2 near here]

When asked about the level of satisfaction with the relevant HoM Family Caregivers session, all carers responded positively. Overall experience was rated only positively (38% positive; 62% extremely positive). Other items were also rated 100% positive: 'Information about HoM' (41% positive; 59% extremely positive) and 'Relevance of the documentary films on dementia care' (21% positive; 79% extremely positive) (Figure 2) and reinforced by the qualitative data: *Powerful personal video stories focusing thoughts on how we can all respond to improve life for people with dementia* (Table 4, Quote 6).

When asked what they ‘most enjoyed about the HoM Family Caregivers’, more than half of the participants (55.2%) stated the positive experience created by educators and staff, and nearly one-third (24.1%) referred to getting to know more about dementia (Figure 2). Through observation, it was evident that participants felt enabled to share their own, real stories, which in turn enabled others to do the same, through peer support and recognition. The skilled facilitation of the sessions by museum professionals was an essential factor in enabling these empathic connections to be made. This included making time to meet and talk with individual participants before the session formally began and unobtrusively asking participants about their interest in the session and personal dementia care experiences. Gradually, as the sessions progressed, participants were sensitively invited by name to share their thoughts and reflections on the session’s content (eg. documentary film stories), encouraging a sense of active engagement and community building, creating a safe, non-clinical space where caregivers were able to feel recognised.

The impact of such interpersonal facilitation has been consistently integral to the success of HoM and is undoubtedly a core cultural quality of the family carers’ adaptation. In this context, the concept and practice of cultural intermediation emerges as significant in generating feelings of trust and ontological security, which are often missing in health and social care environments (Pilgrim et al, 2011). Whereas feelings are usually understood as ‘personal states that somehow belong to us on an individual level’, experiencing the culturally mediated ‘dramatic narration’ of dementia care (via the documentary films), in a carefully facilitated, participatory space, enables the safe social sharing of carers’ feelings and experiences (Highmore, 2017).

Dementia awareness

With reference to dementia awareness, before the session, 24% of participants did not know the stage of dementia of the person they were caring for; more than three in four (76.6%) had never taken part in memory or reminiscence activities at a museum before, but expected to enhance their knowledge of how to support PWD (75.0%). Over 20% of the carers took part in the *HoM Family Caregivers* because they considered that art and cultural activities could help to improve their quality of life and feeling of wellbeing, while 15.6% indicated that '*it is an opportunity for the person I care for to participate in an organised activity'*.

Post-session survey data show that more than three in four considered that *HoM Family Caregivers* was an opportunity to get to know other carers and support services available for carers (75.9%) and to learn more about cultural activities as an alternative to clinical or medical support interventions (75.9%). Furthermore, the vast majority considered that HoM was an opportunity to reduce the perceived stigma associated with dementia by raising awareness (82.8%), to learn about how to live well with dementia (86.2%), and to promote dignity, respect and compassion in care (96.6%) (Table 3).

Similar positive feelings were expressed by the participants in their social media comments (Table 4): *It has taken the fear out of being diagnosed with dementia* (Quote 2); *Powerful. Thought provoking—an eye-opener of the journey ahead. Appreciated looking at the positives: compassion, value, respect and dignity* (Quote 3); *I feel so at home at the HoM!* (Quote 5); and in the comments section of the pre-survey: *I am looking forward to attending this event, and I feel I will learn a lot more to help me deal with my dad*.

Carers' subjective wellbeing

[Table 2 near here]

Table 2 presents the mean scores for changes over time for both subjective wellbeing measures WEMWBS, ZBI, and Smiley-face Assessment Scale. A Wilcoxon signed-rank test demonstrates the *HoM Family Caregivers* did not elicit a statistically significant change in carers' subjective perception of wellbeing (WEMWBS: Z = -1.443, p = 0.149; ZBI: Z = -.400, p =0.689) in the designated period (8 weeks) following participation in the programme.

Nevertheless, an Independent Samples T-Test of the Smiley-face Assessment Scale determines dementia carers reported a statistically significant improvement in their mood immediately after the sessions (t= -2.319 p = 0.021).

Furthermore, qualitative data expresses the positive impact of HoM in the carers' recognition of self-worth: *Knowing that caregivers are just as important as those with dementia. To know you're not alone. Meeting people who understand. Help is out there!* (Table 4, Quote 1).

Museum-led dementia care practices

[Table 3 near here]

Using Falk's (2009) museum visitors' profiles[xi] as a template, half of the respondents identified with attitudes and values close to what this theoretical model describes as *Rechargers* (45%), who tend to visit museums for 'escapist' reasons.

A significant number of carers did not include museum visits/activities (77.00%) in their care practices. However, while the vast majority agreed that using museums for memory or reminiscence activities is essential, 91% had never previously used museums for this purpose. Such cultural practices are considered important for several reasons. Almost one-third of the respondents stated *Improve the quality of life and feeling of wellbeing* (26%) as the main reason for including cultural practice in their dementia care strategies.

Discussion

This study sought to develop an empirical understanding of how a museum-led dementia awareness programme affects carers' care practices and their perceptions of their own wellbeing.

Engaging with and conversing about social history objects, or their representation in the *My House of Memories app*, shifts the focus of care, even if temporarily, from managing the condition to engaging with the PWD on a more person-centred basis. HoM workshops support carers to include cultural activities in their care practices, as a way of creating positive bonding experiences for both carers and PWD. By introducing these positive cultural moments, it is expected that carers' subjective perceptions of wellbeing improve, along with the quality of care they provide. Furthermore, HoM is a strategy that extends the use of the museum as an escapism strategy of the hardships of the caring routine. The museum was a valued and trusted setting with participants experiencing the 'museum effect' (Smith, 2014), while social interaction with peers and the empathic, professional facilitation were also key factors.

i) Increased dementia knowledge and awareness

Getting to know more about dementia was a critical outcome, illustrating the quality of programme content regarding dementia as a clinical condition and its various presentations, along with supporting carers to connect with local organisations such as the Alzheimer's Society.

Participants reported having only known about dementia through their own, often isolated, personal experiences. Through *HoM Family Caregivers* carers learned about clinical definitions of dementia as well as its progression, and demonstrated a shift in their cognitive and emotional understanding of dementia and its implications. This in turn encouraged reflections and re-considerations of care practices, with participants showing an enhanced capacity to consider and assess their own attitudes, encouraging them to feel more interested, optimistic and confident in their caring roles. This is achieved via the powerful empathic qualities of the programme – balanced with informed content and sophisticated delivery – and the way these readily translate into learning outcomes for more person-centred, informal dementia care practice. Hence, this can effectively be described as a culturally (inter)mediated form of *affective practice*, which moves the HoM experience beyond being an affective experience or encounter through its "ongoingness" in encouraging carers to think about the future (Wetherell, 2012).

ii) Improved subjective wellbeing

Perceptions of burden are typically intermediated by sociodemographic characterisations, such as gender, age, economic status, and social and cultural capital (Bourdieu and Passeron, 1990). Equally, coping strategies, personality attributes, and the quality of the relationship between carer and care-recipient (Schulz and Martire, 2004) can influence carers' perceptions of burden. Profiling of care responsibilities shows that research participants were mostly 'care managers' who are married, middle-aged or the older female child of a person living with moderate dementia; they work full time and live independently, with enough money to live on. This group tends to report lower levels of stress compared with other care providers, yet ZBI scores disclosed otherwise (∑ 28.14)[xii] (Zarit et al, 1980; Archbold, 1981). Our sample combines looking after PWD and younger family members, other midlife responsibilities, including work, with an enhanced likelihood of experiencing depression in caring roles. Zwaanswijk et al (2013) argue that carers face challenges regardless of the stage of dementia of the person they care for, as those challenges are mainly due to the carer's struggle to adjust to changes in the behaviour of the PWD.

Quantitative findings suggest family carers experience what Windle et al (2017) describe as the ‘in the moment benefits’ to their wellbeing demonstrated by the immediate pre and post-session evaluations (Smiley-face Assessment Scale), which is potentially strongly linked with the museum setting. Longitudinal assessment of subjective wellbeing and perceived burden also show marginal improvements, albeit within a relatively short timescale (eight-week period before and after participating in the programme).

One resounding result was the realisation among the family carers that they were not alone. The social aspect of the group and peer support were highlighted as important to participants, which reinforces previous studies (Kinney and Rentz, 2005). As such, this is perhaps the least surprising finding, but no less significant for that. Social engagement, and the potential decrease in social isolation, is established as an essential element of wellbeing in older adults, including dementia caregivers (Cherry et al, 2013). However, as noted in other research on museum programmes for PWD (Johnson et al, 2017), increases in wellbeing perceptions are higher during such experiences than in purely ‘social’ settings.

iii) ***Increased engagement with museums and improved creative care practice***

Caring responsibilities (Pickkard et al, 2001) impact negatively on personal time, which subsequently leads to limited time for leisure activities, including museum engagement. Falk (2009) defines those motivated to visit a museum in order to experience restorative moments and escape as *Rechargers*. Considering that the ZBI mean score indicates *HoM Family Caregivers* participants are at risk of depression, it is understandable that museums can act as contemplative places for physical, intellectual and emotional recharge, even if they are enjoyed mostly in an instantaneous capacity.

Alongside the valuable intermediary skills of museum professionals already described, the study also explored how the process of engaging with social history and other collections in museum spaces affects carers' perceptions and uses of more creative, non-clinical approaches.

Considering such interventions in the practice of informal person-centred dementia care helps to examine the unique role that museums can play in contributing to healthier communities through using museum collections to encourage wellbeing and promote health outcomes (Dodd and Jones, 2014). Shared, enjoyable cultural activities and meaningful communication help to strengthen the relationship between carer and care receiver, reinforcing positive feelings associated with culture.

Participants placed a high degree of trust in museums as welcoming, inspiring public places, and were appreciative of the reflective time 'away from' their immediate care environment, in a more stimulating, creative space. Activities that draw heavily on reminiscence therapy techniques were particularly impactful and reinforced the personal resonance of museums, particularly in terms of encouraging carers to see the 'real person' behind dementia and create a more empathic connection in a care context. The professional skills of museum staff in facilitating these sessions were also crucial in emphasising the unique contribution of museums, their collections and the people who work in them concerning reminiscence techniques and dementia care. In this context, therefore, affective (care) practices are also encouraged through the emotionality of responses to social history objects and museum collections, which was evident throughout all ethnographic fieldwork and observations of sessions. In previous studies of emotion and affective heritage practices, emotion is described as action-oriented in that it 'pushes people to do things' and thus deepens understanding of how 'people develop attachments and commitments to the past, things, beliefs, places, traditions and institutions' (Smith et al, 2018). It is possible to observe therefore, how the emotive, formative experiences of HoM as affective cultural work are helping carers to connect to PWD in a more person-centred capacity.

Conclusion

HoM Family Caregivers has had a profound impact in relation to the ‘culture of care’ across the three regions, which can be attributed to the empathic qualities and personal resonance inherent in the programme’s cultural content, design and delivery. While standardised measures did not demonstrate statistically significant longer-term impact on carers’ burden, thematic analysis, individual perceptions, and immediate mood measures illustrated the experiential value of *HoM Family Caregivers* to the emotional wellbeing and affective practice of participating carers.

The research contributes to the accelerating arts and health agenda by demonstrating the value of museums as anchor community assets in health and social care, with many of the positive attributes of NML’s dementia awareness programme being applicable and transferable to a number of care contexts. More specifically, research on the value of museums in dementia care contributes to scholarly understanding of care practice, training and development, by exploring the relationship between cultural intermediation, emotions and affect, and how these can (potentially) be more usefully applied across the health and social care spectrum. This research forms part of a wider body of work led by authors on the value of cultural work in public policy contexts, including criminal justice, as well as health and social care, designed to encourage a more careful, values-based approach to cultural and public policy making.

Bibliography

All-Party Parliamentary Group on Arts, Health and Wellbeing (2017) *Creative health: The arts for health and wellbeing,* London: All-Party Parliamentary Group on Arts, Health and Wellbeing.

Alzheimer's Society (2016, February 4) *Carers for people with dementia struggling in silence,* https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2552

Archbold, P. (1981) Impact of parent caring on women, *XII International Congress of Gerontology*. Hamburg: International Congress of Gerontology.

Ballesteros, J., Santos, B., Gonzalez-Fraile, E., Munoz-Hermoso, P., Domınguez-Pancho, A. I. and Martın-Carrasco, M. (2012) Unidimensional 12-Item Zarit caregiver burden interview for the assessment of dementia caregivers’ burden obtained by item response theory, *Value in Heath* 15: 1141-7.

Bourdieu, P. and Passeron, J. C. (1990) *Reproduction in education, society and culture,* London: Sage.

Brooker, D. (2007) *Person-centred dementia care: making services better,* Jessica Kingsley: London.

Burawoy, M. (2000) *Global ethnography: forces, connections, and imaginations in a postmodern world*, Berkeley: University of California Press.

Camic, P. M., Baker, E. L. and Tischler, V. (2015) Theorizing how art gallery interventions impact people with dementia and their caregivers, *The Gerontologist,*56(6): 1-10.

Camic, P., Tischler, V. and Pearman, C. H. (2014) Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers, *Aging & Mental Health* 18(2): 161-8. doi:10.1080/13607863.2013.818101

Cherry, M., Salmo, P., Dickson, L., Powell, D., Sikdar, S. and Ablett, J. (2013) Factors influencing the resilience of carers of individuals with dementia, *Reviews in Clinical Gerontology,* 23(4): 251-66.

Creswell, J. and Plano Clark, V. (2017, 3rd ed.) *Designing and conducting mixed methods research.* London: Sage.

Department of Health (2009) *Living well with dementia: A national dementia strategy.* London: The Stationery Office.

Dodd, J. and Jones, C. (2014) *Mind, body, spirit: How museums impact health and wellbeing,* Leicester: Research Centre for Museums and Galleries.

Donaldson, C., Tarrier, N. and Burns, A. (1997) The impact of the symptoms of dementia on caregivers, *British Journal of Psychiatry,* 170: 62-8.

Falk, J. (2009) *Identity and the museum visitor experience,* London: Routledge.

Falk, J. H. and Dierking, L. D. (2016) *The museum experience revisited.* London: Routledge.

Fancourt, D. and Finn, S. (2019) *What is the evidence on the role of the arts in improving health and well-being? A scoping review,* Copenhagen: WHO Regional Office for Europe.

Ganga, R., Whelan, G. and Wilson, K. (2017) *Evaluation of the House of Memories Family Carers Awareness Day,* Liverpool: Institute of Cultural Capital.

Highmore, B. (2017) *Cultural feelings: mood, mediation and cultural politics.* London: Routledge.

Hunt, B., Truran, L. and Reynolds, F. (2018) "Like a drawing of breath": leisure-based art-making as a source of respite and identity among older women caring for loved ones with dementia, *Arts & Health,* 10(1): 29-44. doi:10.1080/17533015.2016.12

Kinney, J. M. and Rentz, C. (2005) Observed wellbeing among individuals with dementia: Memories in the making, an art program, versus other structured activity, *American*

Journal of Alzheimer's Disease and Other Dementias, 20: 220-7. doi:doi:10.1177/1533317505020

Kinsey, D., Lang, I., Orr, N., Anderson, R. and Parker, D. (2019) The impact of including carers in museum programmes for people with dementia: a realist review, *Arts & Health*, 1-20. doi:10.1080/17533015.2019.1700536

Lackoi, K. e. (2016) *Museums for health and wellbeing: A preliminary report, National Alliance for Museums, Health and Wellbeing,* National Alliance for Museums, Health & Wellbeing, https://museumsandwellbeingalliance.files.wordpress.com/2015/07/museums-for-health-and-wellbeing.pdf

Lamar, K. L. and Luke, J. J. (2016) Impacts of art museum-based dementia programming on participating care partners, *Journal of Museum Education*, 41(3): 210-9, doi:10.1080/10598650.2016.1193314

Logsdon, R., Mccurry, S. and Teri, L. (2007) Evidence-based psychological treatments for disruptive behaviors in individuals with dementia, *Psychology and Aging* 22(1): 28-36.

MacPhersona, S., Birdab, M., Andersonab, K., Davisa, T. and Blair, A. (2009) An art gallery access programme for people with dementia: 'You do it for the moment', *Ageing and Mental Health* 13(5): 744–52.

McGuigan, K. A., Legget, J. A. and Horsburgh, M. (2015) Visiting the museum together: Evaluating a programme at Auckland Museum for people living with dementia and their carers, *Arts & Health*, 7(3): 261-70, doi:10.1080/17533015.2015.1045531

Musella, O., Carloni, A., De Marino, L., Di Bartolo, E., Gaeta, G., Di Maggio, P. and Fasanaro, A. M. (2009) Visual art improves communication and behaviour of AD patients, *New trends in alzheimer and parkinson related disorders: ADPD*, 15-20.

Nicholls, J., Lawlor, E., Neitzert, E. and Goodspeed, T. (2012) *A guide to social return on investment*, http://www.thesroinetwork.org/publications/publications

O'Shaughnessy, M., Lee, K. and Lintern, T. (2010) Changes in the couple relationship in dementia care: Spouse carers' experiences, *Dementia,* 9(2): 237–58, doi:https://doi.org/10.1177/1471301209354021

Office for National Stratistics. (2015) *Deaths registered in England and Wales (Series DR): 2015*, London: Office for National Statistics.

Pickkard, S., Shaw, S. and Glendinning, C. (2001) Health care professionals' support for older carers, *Ageing & Society*, 20(6): 725-44.

Pienaar, L. and Reynolds, F. (2015) 'A respite thing': A qualitative study of a creative arts leisure programme for family caregivers of people with dementia, *Health Psycology Open*, 2(1): 1-11, doi:10.1177/2055102915581563

Ranasinghe, C., Fleury, A., Peel, N. and Hubbard, R. (2017) Frailty and adverse outcomes: impact of multiple bed moves for older inpatients, *International Psychogeriatrics,* 29(2): 345-9.

Rosenberg, F. (2009) The MoMA Alzheimer's Project: Programming and resources for making art accessible to people with Alzheimer's disease and their caregivers. *Arts & Health,* 1(1): 93-7, doi:10.1080/17533010802528108

Schoenmakers, B., Buntinx, F. and De Lepeleire, J. (2009) The relation between care giving and the mental health of caregivers of demented relatives: a cross-sectional study. *European Journal of General Practice,* 15(2): 99- 106, doi:10.1080/13814780903064455

Schulz, R. and Martire, L. (2004) Family caregiving of persons with dementia, *American Journal of Geriatric Psychiatry,* 12: 240–49.

Secker, J., Hacking, S., Spandler, H., Kent, L. and Shenton, J. (2007) *Mental health, social inclusion and arts: Developing the evidence base*, London: National Social inclusion Programme.

Smith, J. K. (2014) *The museum effect: How museums, libraries and cultural institutions educate and civilize society,* New York: Rowman & Littlefield.

Sörensen, S., Duberstein, P., Gill, D. and Pinquart, M. (2006) Dementia care: mental health effects, intervention strategies, and clinical implications, *The Lancet Neurology,* 5(11): 961-73.

Spector, J. and Tampi, R. (2005) Caregiver depression, *Annals of Long-Term Care: Clinical Care Aging*, 13(4): 34-40.

Throsby, D. (2001) *Economics and culture*, Cambridge: University of Cambridge Press.

Torti, F., Gwyther, L., Reed, S., Friedman, J., and Schulman, K.A. (2004) A multinational review of recent trends and reports in dementia caregiver burden, *Alzheimer Disease and Associated Disorders,*18: 99-109.

Wetherell, J. L. (2012) Complicated grief therapy as a new treatment approach, *Dialogues in Clinical Neuroscience,* 14(2): 159.

Wilson, K. and Grindrod, L. (2013) *An evaluation of House of Memories dementia training programme: Northern model*, Liverpool: National Museums Liverpool.

Wilson, K. and Whelan, G. (2014) *An evaluation of House of Memories dementia training programme: Midlands model,* Liverpool: National Museums Liverpool.

Wilson, K. and Whelan, G. (2016) *Evaluation of the pilot House of Memories Train the Trainer programme,* National Museums Liverpool: Liverpool.

Zarit, S., Reever, K. and Bach-Peterson, J. (1980) Relatives of the impaired elderly: Correlates of feelings of burden, *Gerontologist*, 20(6): 649-55.

Zwaanswijk, M., Peeters, J. M., Beek, A. P., Meerveld, J. H. and Francke, A. L. (2013) Informal caregivers of people with dementia: Problems, needs and support in the initial stage and in subsequent stages of dementia: A questionnaire survey, *The Open Nursing Journal,* 7: 6–13.

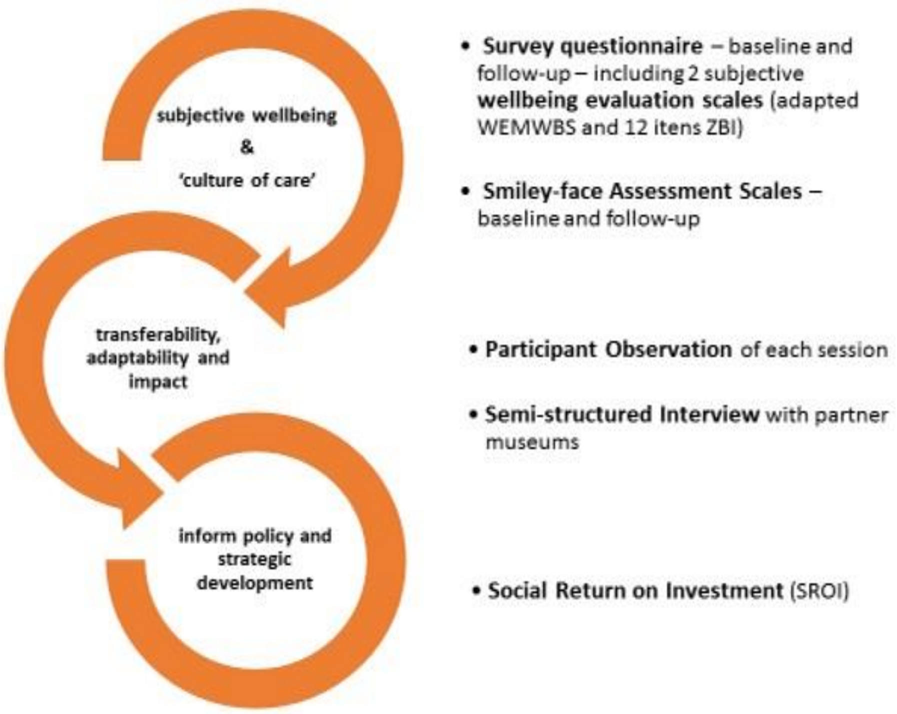

Figure 1 – *TITLE OF THE RESEARCH PROJECT* Work Package 2 research methodology design

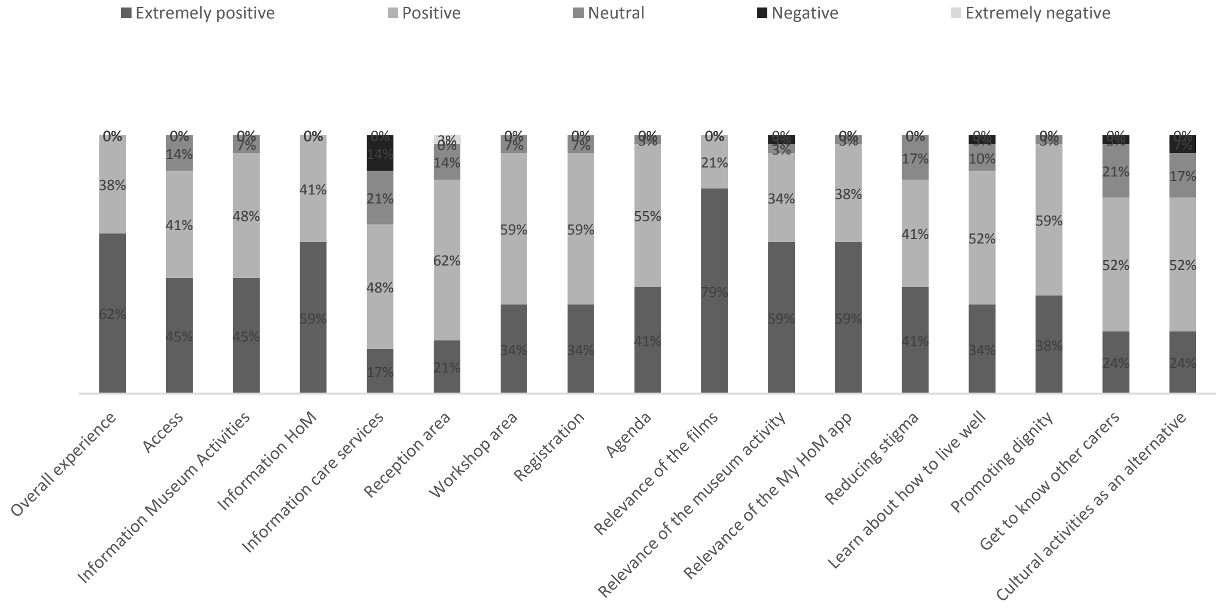

Figure 2 – House of Memories family caregivers' overall level of satisfaction [n= 64]

Table 1- Characteristics of the survey’s respondents

		British Museum		**Museum of Liverpool**		**New Walk Museum and Art Gallery**		**Salford Museum and Art Gallery**		**Total Sample**	
		(n= 19)		**(n= 22)**		**(n= 20)**		**(n= 3)**		**(n= 64)**	
Age	Mean (SD)	53.21	24.10	62.45	19.66	65.20	16.44	41.00	14.42	59.56	20.60
Gender	Female, *n (%)*	15.00	78.95	15.00	68.18	16.00	80.00	3.00	100.00	49.00	76.56
Ethnic group	White – British, Irish, other, *n (%)*	10.00	52.63	17.00	77.27	16.00	80.00	3.00	100.00	46.00	71.88
Marital status	Married, *n (%)*	7.00	36.84	9.00	40.91	12.00	60.00	1.00	33.33	29.00	45.31
Work status	Employed by someone else (full-time*), n (%)*	6.00	31.58	7.00	31.82	4.00	20.00	1.00	33.33	18.00	28.13
	Employed by someone else (part-time), *n (%)*	5.00	26.32	4.00	18.18	4.00	20.00	1.00	33.33	14.00	21.88
Financial situation	I have enough money, *n (%)*	10.00	52.63	10.00	45.45	13.00	65.00	2.00	66.67	35.00	54.69
Nature of the relationship PWD	I am his/her son/daughter, *n (%)*	8.00	42.11	9.00	40.91	6.00	30.00	2.00	66.67	25.00	39.06
Cohabitation PWD	No, *n (%)*	12.00	63.16	16.00	72.73	13.00	65.00	3.00	100.00	44.00	68.75
Hours p/ week spend on personal care	Mean (SD)	5.40	7.55	4.93	8.23	4.25	6.36	5.00	7.81	4.91	7.26
Hours p/ week spend on domestic care	Mean (SD)	10.60	12.00	10.53	13.21	15.33	16.62	12.67	15.31	11.91	13.61
Years caring for the PWD	Mean (SD)	2.50	1.86	3.61	5.48	3.18	2.77	2.67	1.53	3.09	3.64
Stage of dementia	Moderate, *n (%)*	7.00	36.84	7.00	31.82	10.00	50.00	3.00	100.00	27.00	42.19
Ever used an iPad or other type of digital tablet to do memory activities	No, *n (%)*	15.00	79.00	11.00	0.50	12.00	0.60	3.00	1.00	41.00	64.00
Ever taken part in memory or reminiscence activities at a museum	No, *n (%)*	16.00	84.00	16.00	73.00	14.00	70.00	3.00	100.00	49.00	77.00

Table 2 - Longitudinal changes on subjective perceptions of caregivers' wellbeing

			Descriptive n= 21		**Evolution over time**	
			mean	*(SD)*	*Z*	*p*
WEMWBS	**Interested**	Baseline	4.29	0.96	-0.618	0.537
		Follow-up	4.52	0.68		
	Optimistic	Baseline	3.05	1.07	-1.224	0.221
		Follow-up	3.38	1.07		
	Feeling Good	Baseline	2.71	1.15	-1.174	0.240
		Follow-up	3.19	1.03		
	Cheerful	Baseline	2.71	1.10	-1.301	0.193
		Follow-up	3.19	0.93		
	Confident	Baseline	3.00	0.95	-1.854	0.064
		Follow-up	3.52	0.75		
	Total	Baseline	4.29	0.96	-1.443	0.149
		Follow-up	4.52	0.68		
ZARIT	**Not enough time for myself**	Baseline	2.29	1.15	-0.453	0.651
		Follow-up	2.48	0.98		
	Stressed for caring & other responsibilities	Baseline	2.33	1.32	-0.995	0.320
		Follow-up	2.71	1.01		
	Relative's dependence on you	Baseline	2.48	1.25	-1.056	0.291
		Follow-up	2.86	0.96		
	Strained by relative	Baseline	2.33	1.35	-3.190	0.750
		Follow-up	2.19	0.87		
	Health decrease	Baseline	1.90	1.22	-0.894	0.372
		Follow-up	2.24	0.94		
	Lack of privacy	Baseline	2.24	1.26	-0.416	0.677
		Follow-up	2.43	0.98		
	Lack of social life	Baseline	2.29	1.45	-0.957	0.339
		Follow-up	2.67	1.20		
	Unable to care much longer	Baseline	1.62	1.24	-0.029	0.977
		Follow-up	1.57	0.98		
	Lost control of life	Baseline	2.43	1.33	-0.178	0.859
		Follow-up	2.57	0.81		
	Leave the care to someone else	Baseline	2.14	1.24	-0.602	0.547
		Follow-up	2.38	0.97		
	Uncertain about what to do	Baseline	2.33	1.11	-0.465	0.642
		Follow-up	2.14	1.11		
	Overall feeling of burden	Baseline	2.10	1.34	-0.424	0.672
		Follow-up	1.90	0.77		
	Total	Baseline	26.48	11.77	-0.400	0.689
		Follow-up	28.14	7.00		
			n= 147		*T*	*P*
Smiley-face scale		Baseline	10.16	24.10	-2.319	**0.021**
		Follow-up	18.01	33.19		

Table 3 – Dementia Awareness

		British Museum		**Museum of Liverpool**		**New Walk Museum and Art Gallery**		**Salford Museum and Art Gallery**		**Total Sample**	
		(n= 19)		**(n= 22)**		**(n= 20)**		**(n= 3)**		**(n= 64)**	
		n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Expectations	*Enhance my knowledge of how to support people with dementia*	14	73.7	15	68.2	16	80.0	3	100	48	75.0
Reasons participate in memory or reminiscence activities in museums or galleries	*Art and cultural activities can help to improve quality of life and feeling of wellbeing*	3	15.8	6	27.3	4	20.0	1	33.3	14	21.9
	An opportunity for the person I care for to participate in an organised activity	4	21.1	0	0.0	6	30.0	0	0.0	10	15.6
Overall (Net Positive)	*Opportunity to reduce the perceived stigma associated with dementia by raising awareness*	8	88.9	10	90.9	6	66.7	0	0.00	24	82.7
	Opportunity to learn about how to live well with dementia	6	66.7	10	90.9	9	100	0	0.00	25	86.2
	Opportunity to promote dignity, respect and compassion in care	9	100	10	90.9	9	100	0	0.00	28	96.5
	Opportunity to get to know other carers and support services available for carers	6	66.7	10	90.9	6	66.7	0	0.00	22	75.9
	Opportunity to learn more about cultural activities as an alternative to clinical or medical support interventions	6	66.7	8	72.7	8	88.9	0	0.00	22	75.9

Table 4 - Themes, categories and representative data extracts from thematic analysis of the caregivers' social media comments

Themes	**Categories**	**Quotes from the participants' social media comments**
Recognition of self-worth		1. *Knowing that caregivers are just as important as those with dementia. To know you're not alone. Meeting people who understand. Help is out there!*
Dementia care and awareness	Dementia awareness	2. *It has taken the fear of being diagnosed with dementia*

***House of Memories'* Session**	Dementia care	3. *Powerful. Thought to provoke. An eye-opener of the journey ahead. Appreciated looking at the positives: compassion, value, respect & dignity.*
	Dementia characteristics (uniqueness)	4. *Realising everyone's experience with dementia is different*
	House of Memories team	5. *I feel so at home at the HoM! Our brother from another mother.*
	My House of Memories app	6. *Learning about the app was very useful & feel that will benefit Mum. Certainly, help with conversation.*
	Museum activities	7. *Let them show you the world through their eyes - find the memory, build the conversation.*
	Documentary videos	8. *Powerful personal video stories focusing thoughts on how we can all respond to improve life for people with dementia.*

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[i] https://houseofmemories.co.uk/

[ii] In the scope of this research, we use the concept of burden as it is defined by Zarit et al (1980).

[iii] *here: now* at The Frye Art Museum, Seattle; *Meaningful Moments* at the Dallas Museum of Art, Texas; and *Minds on Art* at the Detroit Institute of the Arts, Michigan (Lamar & Luke, 2016).

[iv] http://iccliverpool.ac.uk/crossing-boundaries/

[v] The term “mixed methods” refers to a research methodology that integrates quantitative (closed-ended) and qualitative data (open-ended) within a single research design. The premise of this research methodology is that such integration allows a more comprehensive utilization and interpretation of data and, as such, more accurate results (Creswell and Plano Clark, 2017).

[vi] The five items include measures of interest in new approaches to dementia care; optimism; feeling good about oneself; cheerfulness and confidence.

[vii] Tested within Midlands model (2014) and Pilot House of Memories Train the Trainer Programme (2015/2016).

[viii] Not enough time for myself; Stressed by caring and other responsibilities; Relative’s dependence on you; Feeling strained due to relative; Health decrease; Lack of privacy; Lack of social life; Unable

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to care much longer; Lost control of life; Leave the care to someone else; Uncertain about what to do; Overall feeling of burden.

[ix] Two further data collection techniques were conducted within the scope of *TITLE OF THE RESEARCH PROJECT*, however the data collected in those are not used in this paper. A series of eight semi-structured recorded interviews (30–60 min) with museum staff were conducted by the first author. A Social Return on Investment (SROI) workshop was also run in order to determine the social value and relative cost benefit of the *House of Memories Family Carers Awareness Day* (Nicholls et al, 2012; Throsby, 2001).

[x] Three categories (carers' self-recognition, dementia care and awareness, and HoM session), and seven sub-categories (dementia awareness, dementia care, dementia characteristics, HoM team, *My House of Memories app*, museum activities, documentary videos).

[xi] John Falk (2009) perceives museum visits as part of people's lives. This author has been developing a model of visitor experience analysis that reconceptualises the field from a holistic perspective using the 'lens' of visitors' identity and motivations. The model proposes to understand visitor experiences in the scope of their own identity, decision-making and meaning-making strategies, memory, and leisure preferences; in this sense, he tries to see visitors beyond their socio-demographic features. Five key types of visitors were identified: i) Explorers (motivated by personal curiosity); ii) Facilitators (motivated by other people and their needs); iii) Experience-Seekers (motivated by the desire to see and experience a place); iv) Professional/Hobbyists (motivated by specific knowledge-related goals); v) Rechargers (motivated by a desire for a contemplative or restorative experience). The fact that one person can have different experience types at different moments in different museums does not mean that the diversity of that experience is not relevant and cannot be captured. Falk's initial model has been extensively used, criticised and even extended (Falk and Dierking, 2016).

[xii] A cut-off score above 24 has significant predictive validity for identifying caregivers at risk for depression (Schreiner et al, 2006).

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