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“A respite thing” – A qualitative study of a creative arts leisure programme for family caregivers of people with dementia

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Abstract

This study explored the meanings of participating in a five-week creative arts leisure programme designed for family caregivers of people with dementia, using interpretative phenomenological analysis. Eight carers attended and four who met the eligibility criteria agreed to be interviewed. Participants experienced the arts group as providing a sense of freedom and respite, strengthening identity through promoting achievement, offering social support through a collective focus on art- and craft-making, and increasing resilience for coping with caring. Some found the five-week programme too short. Benefits were linked to the security of knowing that loved ones with dementia were close by, being well cared for. Further research is needed into the longer-term benefits of creative arts groups for promoting carer well-being.

Key words: arts for health, carers, dementia, well-being

Introduction

This paper focuses on the meanings of a creative arts leisure programme designed for caregivers of people with dementia. Outreach tutors from a South London art gallery conducted four 90-minute art- and craft-making sessions within a Healthy Ageing Café in an inner London Borough. The programme was designed in conjunction with carers who attended the café with their loved ones affected by dementia. During the carers' arts programme, the people with dementia were cared for elsewhere, within the familiar environment of the café. The four sessions were followed by a joint art gallery visit for caregivers and their loved ones with dementia, where they saw the group's creative products on public display alongside other artwork from the gallery's collection.

Whilst informal caregivers are recognised as a crucial resource for people with dementia, many experience considerable stress and health problems. They report more depression and anxiety than demographically-matched people without caring responsibilities (Lavela and Ather, 2010), and are at greater risk of depression than those who care for older people with other chronic conditions (Schoenmakers et al., 2010). Some spouse caregivers describe struggling to preserve a sense of connectedness within their marital relationship, a loss of identity and inability to meet their own needs (Gahagan et al., 2007; O'Shaughnessy et al., 2010). These losses may be compounded by reductions in leisure, social activities and other meaningful occupations (Clark and Bond, 2002; Hwang et al., 2009). Female caregivers, in particular, may feel unable to accept day-time respite services from feeling that, as women, they are obliged to care and unentitled to leisure (Strang, 2001). In addition to experiencing stress and loss, caregivers of people with dementia are also more vulnerable to declining physical health (Pinquart & Sörensen, 2007), particularly in contexts of socioeconomic hardship and inadequate support. Nonetheless, positive aspects of dementia care-giving also need acknowledgment such as personal growth, resilience and spirituality (Netto et al., 2009).

There is some recognition that leisure activities offer a buffer against stress, and have health-protective effects, especially among less socially advantaged people (Iwasaki, 2006). Leisure activities potentially reduce caregiver burden (Losada et al., 2010). Some caregivers view leisure as a temporary escape from caring, which helps to preserve health and emotional functioning, thereby enhancing coping (Gahagan et al., 2007). However, some describe feeling too overwhelmed by obligations and guilt in relation to caring to take any leisure breaks (Gahagan et al., 2007; Schumacher et al., 2012). For some whose lives are dominated by care-giving and exhaustion, making time for leisure can be seen as an additional burden - "one more thing they "had to do"" rather than presenting opportunities for choice or relaxation (Gahagan et al., 2007; p. 59). Taking time for self away from the cared-for person also entails access to alternative care arrangements. Shanley (2006) suggested that brief experiences of leisure could provide a creative form of respite for carers, enjoyed whilst their loved ones with dementia were being well cared for by others. However, the forms of leisure that were envisaged consisted of 'pampering'

and passive entertainment, rather than activities that invite active engagement, challenge or development of new skills.

There is increasing recognition that engagement in creative art-making may offer a source of health and subjective well-being, with suggestions that this is a topic that requires more research (Camic, 2008; Clift et al 2009; Mowlah, Niblett, Blackburn, & Harris, 2014; Murray & Gray, 2008). Furthermore, museums, art galleries and other cultural resources are now being regarded as promoting public health (Camic & Chatterjee, 2013).

A number of literature reviews have summarised evidence about the benefits of visual art-making for health and well-being, in medical contexts (Staricoff, 2004; Stuckey & Nobel, 2010), for people with mental health problems (Hacking, Secker, Kent et al., 2006; Heenan, 2006; Leckey 2011; Spandler et al., 2007) and older people (Castora-Binkley et al., 2010). Recurring themes are that engagement in art-making reduces stress, facilitates contact with more positive emotions, increases self-worth, and promotes feelings of social connectedness. The review by Perruzza and Kinsella (2010) adds that creative arts interventions commonly enhance perceived control and sense of purpose, and may transform the illness experience. Such reviews commonly observe that evidence about outcomes is weak with very few studies including control groups or random sampling. Yet as Castora-Binkley et al., (2010) point out, people tend by virtue of their own interests to opt in or out of creative leisure interventions and retain a high level of personal influence over their activities within such interventions. So for ethical and practical reasons, randomised controlled designs, regarded as preferable in many fields, are rarely selected for research into the effectiveness of creative art-making programmes.

Few studies have explored the benefits of creative art-making programmes for carers. Camic et al. (2014) offered carers and people with dementia eight two-hour joint sessions based in two art galleries, involving viewing and discussion of selected items of art displayed in the gallery, as well as personal art-making. The reported findings focused primarily on benefits for participants with dementia (described by themselves or their caregivers), such as increased cognitive engagement, reminiscence, new learning and social inclusion. There was less detailed analysis of

caregivers' experiences of this creative intervention. The intervention achieved no change in the quantitative measure of caregiver burden although qualitative accounts suggested that caregivers enjoyed the social aspects of the intervention.

Although evidence is limited, it suggests that a creative arts intervention may offer caregivers multi-faceted experiences that promote subjective well-being, such as hope, affirmation, and mutual support.

Purpose of this study

The research objective was to explore the meanings of a creative arts leisure intervention for caregivers of family members with dementia.

Method

A qualitative research approach was appropriate to gain a rich 'insider' perspective. Interpretative phenomenological analysis (IPA) has underpinned previous research into the creative process (e.g. Lawson et al., 2014; van Lith et al., 2011) and provided insight into the challenges of caregiving (O'Shaughnessy et al., 2010). This is an approach that values detailed idiographic analysis of small numbers of participants to obtain rich understandings of their shared *and* distinctive experiences (Smith et al 2009). Researchers' own contribution to interpreting and bringing theoretical understanding to participants' accounts is acknowledged. In this study, it was considered helpful for each author to bring different professional backgrounds (occupational therapy and health psychology) to the analysis process.

Ethics

The project was approved by the university ethics committee. People attending a healthy ageing café in an inner London borough were made aware of the creative arts intervention through posters displayed within the café. Anyone interested in attending was then provided with detailed written information. For ethical reasons, caregivers were informed that they could choose to participate in the creative programme without taking part in the research interviews. Carers were also reassured that their attendance at the healthy ageing café was not in any way affected by their decision to take part or not in the creative arts project. They had to attend at least 3 of the 4 art-making sessions to be eligible to be interviewed. Those

agreeing to be interviewed gave written consent. All stated names (of participants, and any other person referred to in interviews) are pseudonyms.

The intervention

The creative arts intervention comprised four sessions of art-making in the carers' group, and one free-of-charge visit to a prestigious local art gallery accompanied by the loved one with dementia. In the preliminary stages of designing the programme, both carers attending the café and outreach tutors from the local art gallery were consulted. The practical sessions were 1.5 hours weekly, facilitated by an arts tutor from the local art gallery (with an arts, not therapy, background), and a trained staff member from the Alzheimer's Society. Both were familiar with managing group dynamics in a sensitive way. There were no fees for attending and no particular requirements concerning the caregiver's status or severity of the loved one's illness. The practical creative art-making sessions followed a person-centred philosophy, with participants able to choose from among a range of arts and crafts each week. There were no ground rules about what could/ could not be expressed. Caregivers were free to communicate their care-giving experiences in words or nonverbally through their art if they wished, or to focus on other topics during the art-making sessions.

Participants

Four of the eight participants who attended the creative arts programme gave written consent to join the research. This sample comprised two female spouse caregivers (Maggi and Doreen), one male spouse caregiver (Bob), and one daughter caregiver (Lydia), with ages ranging from 50–79 years approximately. All were Caucasian, spoke fluent English and lived in inner London, and appeared to be of lower socioeconomic status. Small samples allow in-depth analysis, and are valued in IPA studies (Smith et al., 2009).

Regarding the four who were not interviewed, two male participants opted out of the programme after the initial session to continue to participate with their loved ones in the Café's regular activities. One male carer's spouse became unwell towards the latter end of the programme which prevented him from participating in the carers' art programme, although he was still attending the café. One male with an ethnic

minority background did not attend the carers' art intervention sufficiently to meet the inclusion criterion.

Data collection

Semi-structured interviews were carried out in privacy, in a room within the café by the first author within a week following the conclusion of the creative art intervention, so that the memory of their experience was still fresh. Although involved in the initial design of the programme and liaison with the art gallery, the interviewer had played no part in the intervention, and had not observed participants during their creative activities. This was thought to reduce any pressure on participants to 'reward' the facilitators who provided the creative arts experience by inflating positive feedback. A topic guide (Table 1) offered some structure, but the intention was to follow the participants' own accounts of their lived experiences in a flexible, sensitive way. Interviews were about 50 minutes long.

----- Insert Table 1 about here-----

Fairly straightforward questions were asked at the beginning to ease potentially burdened caregivers into talking about their experiences. More exploratory and sensitive questions were sequenced in the middle of interview, and the final two questions helped to lighten the emotional tone. The guide was nonetheless used flexibly, respecting the participants' own priorities.

Data analysis

Interviews were digitally recorded and transcribed verbatim. As part of the immersion process, the first author also listened a few times to the audio-recordings before transcribing and analysing. It became apparent from the interview data that to understand the meanings of the creative art group, there also needed to be analysis of the care-giving experience that participants also described at some length in the interviews. Their accounts of care-giving revealed psychological needs that the art-making group may have helped to address. Following the guidelines of Smith et al (2009), the initial stage of data analysis was idiographic, starting with identification of

specific meanings through marginal comments, and then moving to inferring broader themes. Both authors conducted this process independently in the initial stages, charting themes and subthemes. Through cross-case analysis, the authors then looked for convergent themes, and followed usual IPA practice (e.g. Van Dijkhuizen et al., 2006) in seeking to resolve differences by discussion and going back to the data, rather than seeking any form of quantitative agreement. The authors sought to maintain a 'phenomenological attitude' 'reflexively restraining pre-understandings' (Finlay, 2008:1), albeit within limitations, as IPA methodology regards researchers as bringing their own interpretative lenses to the task of understanding participants' accounts. Reflexivity, sensitivity to context, and attention to divergent as well as convergent themes were all strategies that helped to increase credibility. To help maintain a sense of the first person accounts, all themes and subthemes are tagged with a relevant quotation. Transferability of findings cannot be assumed. Rather, readers need to assess the similarity between the context of this study and others (Smith et al., 2009).

Findings

The four caregivers all described experiencing various challenges in their caring role. These are presented in Table 2.

----Insert Table 2 about here-----

In brief, participants described their everyday life as a 'compromised experience', requiring considerable tolerance, ongoing concessions and modified expectations, and loss of self. All described experiencing loneliness and sometimes feeling overwhelmed by their obligations and the constant need to 'think for two' (for example, in anticipating and avoiding risks to the cared-for person). Caregiving depleted their resources, and two of the caregivers feared negative consequences for their own health.

Five convergent themes (some with further sub-themes) encompassed the meanings of the creative art-making group, and will be explored below (Table 3).

---Insert Table 3 about here-----

1. ***“It felt good doing art work”*** – An accumulation of positive influences of art-making on mood and identity.

All four participants were enthusiastic about the creative art-making group, expressing not only pleasure in engaging the creative process but a deep sense of self-affirmation. They took pride in various aspects of their artwork and were sometimes surprised by its quality, and by inference, their own creative abilities:

“I had done something I have never done before and I was pleased with it. So I suppose that made me feel good...I’m so proud of that bag.” (Doreen)

A number of experiences contributed to participants taking pride in their work, including their own aesthetic judgements, and the feedback of tutors and group members. Some took pride in accomplishing more than the tutor had expected in the sessions, and in making items of sufficient quality to be shared as gifts (which in turn communicated their creative abilities to others, and led to positive feedback):

“The bags came out really lovely. I was so proud of them. I didn’t think I could do anything like that. And I made two bags, so my two daughters can have one each.” (Maggie)

The experience of achievement was further enhanced by participants’ experiences of the art gallery visit, where they saw their art products on public display. For example, Lydia said, *“I was shining”*, to describe her excitement at seeing her work displayed alongside acclaimed art from the gallery collection. Lydia expressed a desire to reconnect with her creative self, and was hoping to use the intervention as a springboard to future art-making opportunities:

“I feel I could go back and do something else now” (Lydia)

Whilst two felt able to re-contact previous creative interests through the intervention, two participants (Maggie and Doreen) had never before engaged in art-making as adults. They commented on how the art group had enriched them as persons, exposing them to novel experiences and the opportunity to learn:

“I was never taught nothing, none of them [artistic] things at school. So it’s very interesting knowing all these different things.” (Maggie)

Given their everyday experience of giving constant attention to their loved one and 'thinking for two', they had found the new opportunity to learn to be a refreshing and distinctive experience. Like Lydia, both Maggie and Doreen, expressed a desire to follow up the intervention by engaging in further creative occupations, although they recognised substantial barriers to doing so (associated with their care-giving commitments).

Bob had described himself as having 'always been' interested in art, but like Lydia had not participated for some time, due to his care-giving and other responsibilities. Through the art group, he felt he had re-contacted his creative side:

"For me it got me drawing again...I probably wouldn't have got interested in art again had we not come here" (Bob)

All participants described valuing the expressive element within the creative process.

"Even if you don't feel that you are very creative ... some sort of expression comes out." (Lydia)

The self-expressive nature of art-making offered a source of excitement contrasting with their more mundane 'everyday' obligations:

"I have knitted [before], but that is something completely different, you know, it's art." (Doreen)

Lydia expressed excitement about the incidental or surprise element inherent to art-making:

"You can't see what it's gonna come out like... It is hard to imagine ... until you peel back the lino and the prints come out."(Lydia)

Lydia's account was distinctive in that she initially felt obliged to participate by her friends in the café, rather than having an intrinsic interest. Yet she went on to experience the self-expressive process within this group as stress-relieving:

"First I didn't wanna go into the room even though I'd agreed to it ... but when I came into the room and started to do it... it seemed to lift my mood." (Lydia)

Although Lydia described the art-making mostly as improving her mood, at times she understood her imagery to express sadness and grief:

“I got a bit emotional for doing the flower for my mum, ‘cause you know, obviously I miss her” (Lydia).

The support of the group in such circumstances was highly valued, and will be explored further in the next theme.

2. “Enjoying being together” – group participation motivates participation

All participants highlighted the social benefits of participation in the programme, as well as enjoying the inner experience of creativity. They valued the camaraderie of the group, mutual encouragement, and the respectful input and careful planning of the arts tutor. The group offered a *shared* and mutually affirmative experience:

“Because we were looking at what each other were doing, giving each other praise” (Bob)

These shared positive interactions among peers not only built companionship, but also confidence:

“It build my confidence up a bit, because...we were all commenting on each other’s work... Nice to see what other people can do as well.” (Lydia)

All participants commented on the pre-existing bond between them from their previous meetings in the café, a dynamic that may have strengthened the intimacy and openness between them:

“I think because we knew each other before, you know, it helped”. (Doreen)

Participants highlighted certain similarities between the caregivers’ art group and a discussion-based caregiver support group. Both offered opportunities to share problems, but they valued the art group for having a more enjoyable focus, and relieving the necessity to talk about care-giving:

“Like the normal carer forums we have, we just sit and listen to each other’s solutions to problems, you know what problems they having ... helpful ... but sometimes depressing, whereas this was enjoying being together.” (Bob)

The group was regarded as encouraging and supportive, motivating attendance:

“Working in a group gives you encouragement, you know, to do it, whilst if you were on your own, you would probably not have bothered” (Bob)

Maggie and Doreen thought that the non-judgemental attitude of the group aided trust and self-expression.

“We could sort look at each other’s work and say, oh yeah, oh God, what the hell! ...We could talk while we were doing it ... and it was good.” (Doreen)

No negative dynamics were described. All participants recognised the central role of the facilitators not only in teaching skills for making arts and crafts, but in orchestrating such a supportive environment:

“They just made us feel welcome, made us feel at ease, encouraged.” (Lydia)

Doreen, in particular, highlighted how the facilitators had instilled confidence in their new art-making skills:

“They told us we did wonderful things even though we looked at it and thought they were rubbish, but they boosted your confidence” (Doreen)

Participants also valued the way the facilitators had organised the programme which allowed them to attend without any need to set aside time for preparation:

“Just came to do what was put before me” (Bob)

This preparation enabled participants to take part in the programme without compromising their caring responsibilities. This links with the next theme, experiencing the leisure group as a form of respite.

3. “It was a sort of like a respite thing” – the caregivers’ art group as a space of freedom to allow caregivers to do their “own things”

‘Respite’ refers to a temporary period of rest or relief from something difficult or distressing. Participants regarded the facilitated creative art group as offering respite,

as a space of freedom away from caring, and a symbolic space to allow them to do “their own things”.

“It gave me a couple of hours away from Harry, you know, sort of like respite really, which I know, I won’t normally get ... it was sort of like a respite thing”
(Doreen)

Whilst only one participant (Doreen) explicitly used the term ‘respite’, all participants’ accounts reflected aspects of this concept. A key to the success of the programme as a form of respite or space for stress relief for the caregivers was the security of knowing that their loved ones with dementia were being cared for appropriately in close proximity within the café environment. This security enabled them to forget the worries of care-giving, to focus more deeply on their creative occupations, and interact more fully with other group members and the facilitator. Participants thought that both they and their loved ones experienced a temporary freedom from the intensity of the care-giving and care-receiving relationship. Even so, two described checking on the well-being of their loved ones during the art sessions. This illustrates the interdependence of the couples and perhaps the caregiver’s need to cope with guilt when engaged in a separate activity.

“I would not have participated in it, if I hadn’t been here [at the café] with my wife...I would pop out and then come back again... I just go to see if she was, you know, alright with that” (Bob)

Maggie also found freedom in the art room, feeling it was near enough to her husband and yet separate.

“I don’t know what he was doing out there. So it was quite nice, to just be on our own.” (Maggie)

Maggie expressed a desire to continue her creative artwork, but thought that this was unlikely, without the provision of satisfactory alternative care for her husband

Participants enjoyed respite from care-giving both through spending time immersed in the art-making process as well as participating in the social exchanges surrounding this. This helped them to forget about the outside world temporarily, including their caring responsibilities:

“It did seemed to you know, help me to relax and forget about things” (Lydia)

4. “Easier to care” – influence of the creative arts groups on care-giving

The creative process, as well as the accepting social environment of the art group, were thought to promote relaxation. Three participants experienced this as having longer-term benefits, enhancing their sense of control and providing a resource for care-giving for some time after the end of the sessions:

“It was easier to care, I don’t feel so stressed and under pressure ... when I come away from here.” (Lydia)

“Maybe I can reflect back on how I felt when I was doing the sessions and try to ... calm down that way.” (Lydia)

“You are going to be relaxed when you go outside to your husband.” (Maggie)

It is recognised that as the interviews were conducted within a week after the end of the programme no longer-term benefits could be explored. But in the short-term, the respite experience of the creative arts programme had beneficial ‘ripple out’ effects into the care-givers’ management of the stress of caring, according to their accounts. However, not all the experiences of the creative programme were positive, as shown by the final theme below.

5. “Wasn’t long enough” – Limitations of the programme

Despite clear information about the structure of the programme at the start, three of the participants expressed some dissatisfaction with the number of sessions, their duration each week, and the rather cramped physical space available for the art group.

“Without being rude ... it wasn’t sort of a lot of time.” (Lydia)

At one point in the interview, Lydia also elaborated on her personal limitation, being ‘quite slow working’ which may have exacerbated the problem for her.

Doreen took a more pragmatic approach to the programme's time limitations, appreciating that their loved ones with dementia might be stressed by their care-givers' absence:

"I know we had limited time here ... They're limited on the time because you are with your partner and, you know sometimes ah, I don't know if you [have] noticed, sometimes some of the partners get a bit aerated and ah, [ask] 'where are they'?" (Doreen)

The ending of the programme evoked a mixture of feelings. Maggie and Doreen expressed some sadness at the ending:

"It's sad, very sad... When I went to ... the art gallery, I thought, ah, this is the last time" (Doreen)

Lydia expressed even stronger feelings about the ending of the programme, and seemed to feel cheated out of a precious opportunity:

"It's a bit upsetting, really... 'cause you get to do something and you enjoy it, and then it sort of stops" (Lydia)

Although Bob wanted the programme to be longer, he did not dwell on any negative aspects of the ending. Instead he focussed on the reconnection with his creative self as a positive gain from participating in the programme, and expressed his hope to continue:

"It got me drawing again" (Bob).

Discussion

Although the analyses of the participants' care-giving experiences were conducted separately from the analyses of the meanings of the art-making group, it is clear from comparing Tables 2 and 3 that the creative art programme met certain deep-seated needs arising from giving day-to-day care to a person with dementia. This group, with its variety of affirmative experiences, addressed (albeit in an inevitably limited way) the compromised experience of caring, which required continuous watchfulness (to manage risk, or de-escalate tension, for example), careful negotiation of joint activities, and loss of self. The social processes within the group supplemented, in a

particularly pleasurable way, the support already gained from the carers' group at the Healthy Ageing café. In focusing upon processes and products of art-making, these social interactions helped to strengthen a sense of self that was not, within that art-making space, solely defined by care-giving, or burdened by everyday problems. Guilt, associated with leaving loved ones with dementia to alternative care, was minimised by having them close by, in a familiar supportive environment. Caring was very much experienced as depleting coping reserves, and the art-making group offered a temporary respite. Participants felt that the experience of focusing deeply on creative expression enabled them to return to their care-giving role in a better state of emotional control and relaxation.

The findings suggest that the creative art-making group affirmed a positive identity outside of caring, albeit for a brief period. Furthermore, the care-giver identity was also maintained by having relatives nearby, in close enough proximity to contact if necessary. Tangible artistic products (appraised personally as well as shown to others within the group, displayed more formally in the art gallery, or given as gifts) helped demonstrate participants' capability to self and others. This resonates with evidence that creative occupations strengthen a person's sense of identity beyond the labels imposed by long-term mental and physical illness (Lawson et al., 2014; Stickley and Eades, 2013).

Participants thought they only rarely expressed feelings about caregiving through their artwork, a finding that contrasts with that of Roberts et al. (2011), whose participants were caring for family members with mental health problems. The latter authors found that carers of people with mental health problems tended to interpret the artwork on display in an art gallery through the lens of their care-giving experiences (e.g. viewing the art as metaphorically expressing loss and grief). There was no evidence, from participants' accounts, that facilitators had dissuaded them from such cathartic self-expression. Instead, it appears that the participants created their artwork primarily for pleasure rather than as a form of therapy.

Roberts et al. (2011) also described the gallery experience as offering carers a bridge into new occupations unrelated to mental health settings, and the care-giving role. Some of the caregivers in the current study also expressed a desire to continue

with their newfound creative leisure occupation but acknowledged substantial barriers unless suitable alternative care for their loved ones was provided.

The creative arts group offered camaraderie and participants highlighted that making art together was more pleasurable than problem-focused carer support groups. There was no evidence that facilitators set any ground rules preventing the airing of problems. Similar feedback was elicited by Roberts et al. (2011) in their art gallery intervention for carers of people with mental health problems. The motivating and supportive functions of the group and the tutors (or group facilitators) in community art interventions have been noted in other studies (e.g. Camic et al., 2014; Lawson et al., 2014), and clearly rely on the facilitators' skills not only in presenting interesting art projects but managing group dynamics to enhance the experience of mutual support, respect and sharing.

This study has been relatively unusual in discovering that a creative arts leisure intervention may offer a meaningful form of brief respite to caregivers of people with dementia. Gahagan et al. (2007) also described leisure as having a respite function, although the meanings of specific leisure occupations for caregivers were not explored. Shanley (2006) suggested that brief episodes of pleasurable leisure could be regarded as a form of respite for carers although rather passive occupations were described such as manicures or massage. The creative art-making group in the current study offered opportunities for active learning and self-direction, perhaps strengthening a sense of agency more effectively than passive leisure occupations. It provided caregivers with a symbolic space of freedom, akin to the 'haven away from the rest of life' described by Collie et al. (2006; p 765), and the 'safe harbor' described by Predeger (1996; p.56). Creative arts interventions have been portrayed as offering temporary respite also by la Cour et al. (2005) and Garrett (2014).

Participants in the current study linked the respite experience to having their loved ones nearby. For many care-givers, feelings of guilt and moral obligation act as barriers to taking up leisure opportunities (Argüelles and von Simson 2001; Gahagan et al., 2007). The presence of dependency behaviour or insecure attachment in the person with dementia may also limit caregivers from taking time for leisure (Nelis et al 2013). The close physical proximity of caregivers to their loved ones may have

helped maintain attachment security between the caring dyads, and reduced caregiver worries. By reducing these various barriers, caregivers may have enjoyed more complete immersion in the creative occupation, setting aside their caring concerns temporarily, and achieving flow (Csikszentmihalyi 2002). Resonating with the flow concept, they also described experiences of optimal challenge during art-making, orchestrated by the tutor, promoting confidence and achievement. Csikszentmihalyi (2002) posits that awareness of self is much reduced during flow experiences but emerges more strongly afterwards, enhancing the person's subsequent ability to pursue valued goals, cope with adversity, and take pleasure in everyday events. This theory resonates with the caregivers' descriptions of deriving feelings of calmness from participating in the group which they could then apply in their care-giving roles.

Critical evaluation

Programmes for caregivers need to be designed flexibly around their needs and goals (Zarit and Femia 2008), and carers were involved early on in the design of this intervention. Despite this, most participants found the intervention too short. The problems of managing endings have been noted in previous studies of art-making groups (Lawson et al., 2013, Stacey and Stickley, 2010). Careful attention is needed when designing community art projects to planning suitable follow-up events and opportunities for participants who wish to take their new interests forwards. Previous studies have noted that some participants use arts interventions as 'stepping stones' to new roles and occupations (Heenan 2006). It could be considered unethical to offer participants a highly meaningful, stress-relieving experience without any real opportunity to take it further.

The IPA method was appropriate for exploring caregivers' intertwined experiences of creativity, and wellbeing, an under-researched topic, although this methodology does not enable isolation of effective 'variables' within an intervention. The researchers worked together to verify and challenge emergent themes, starting with an idiographic analysis and using reflexivity to increase awareness of their respective roles within the research process. For example, the first author's background as an occupational therapist would likely encourage appreciation of the psychological importance of active (rather than passive) leisure participation, whilst the second

author's background as a health psychologist was likely to attune her to care-givers' identity issues.

The study sample was small but in line with IPA guidelines (Smith et al 2009), and contained a balance of people with and without previous art-making experience. However, the research lacks the stories of the four caregivers who attended part of the programme but who did not wish (or were not eligible) to be interviewed. For ethical reasons no further enquiry was made of their experience of the intervention, and it is therefore not known if they were less satisfied with it, or not. It is interesting, however, to note that three of the four who were not interviewed returned to taking part in café activities with their loved ones, in preference to being separated.

The first author established trust and rapport when initially planning the intervention with the caregivers at the café. The second author was an 'outsider' to the data collection process, and helped analyse the interview data with a fresh perspective. The context is a clear limitation, with the intervention situated in an inner London borough. Carers from more advantaged backgrounds and with lengthier experience of art-making might have offered richer accounts of the meanings of this creative activity. The findings may not readily transfer to care-givers from more affluent areas who may have more options for maintaining leisure occupations, for paying adult education course fees to enable further arts participation, and/or purchasing professional respite care.

Further research

Additional studies are clearly needed to explore the short-term and longer-term benefits of creative arts interventions for caregivers of people with dementia. Indeed, the value of visual art-making over and above any other form of leisure group for carers needs to be established. The current study focused on a group of participants who were already well known to each other, and the merits and difficulties inherent in joining an unfamiliar creative leisure group could be explored. In particular, participants linked their ability to enjoy relaxation and flow during art-making to the security of having their loved ones nearby. Close physical proximity appeared to help participants manage feelings of guilt and moral obligation that act as barriers to leisure participation and its health-promoting properties, as well as maintaining their

identities as committed carers. Interviewees offered little comment about any guilt and anxiety associated with being separated from their loved one during the creative intervention. But we note that a further three carers who enrolled in the programme preferred to discontinue and return to participating in café activities with their loved ones. Carers' experiences of managing guilt when pursuing independent interests is an issue worthy of further research.

Conclusion

This qualitative study found that a short-term creative arts leisure intervention for carers of people with dementia facilitated self-expression and positive identity, addressing the undermining effects of chronic care-giving on self. The arts group also provided a deep sense of camaraderie and mutual encouragement. Because interaction focused on artistic processes and products, it was regarded as more pleasurable and relaxing than a problem-oriented carers' group. The creative art-making within a supportive social environment helped to alleviate the sense of depletion that carers associated with care-giving and offered a brief experience of respite that they felt enhanced their resilience and coping resources.

Caregivers' needs for psychologically restorative leisure activities are largely overlooked. Museums and art galleries are being increasingly recognised as having a role to play in promoting well-being, being rich in cultural heritage, offering a 'sanctuary' from everyday stress, and promoting cognitive and emotional exploration in a non-stigmatising setting (Camic and Chatterjee, 2013). Further research into the benefits of creative arts interventions for care-givers is recommended.

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Table 1: Topic Guide

1. Could you tell me a little bit about yourself?
2. Can you tell me about when you became a carer and what being a carer involves?
3. How did your interest in participating in this creative leisure group come about?
4. Can you tell me about your experience of this creative programme?
5. Can you describe something about a specific creative activity during the programme that was particularly meaningful or significant to you?
6. What has participating in this programme meant for you?
7. Are there any tips you would like to share with other carers in relation to participating in a creative leisure activity?
8. Is there anything else you would like to add?

Table 2: Caregivers' experiences of caring

Themes/descriptor	Bob	Doreen	Maggie	Lydia
I) Caring as an compromised experience which restricts sense of self and self-expression				
a) <i>"I just had to re-arrange me"</i> - the challenge of preserving a positive sense of self within the caring role	✓	✓	✓	✓
b) <i>"Can't really say what you're wanting to say, and you can't really do what you're wanting to do"</i> – sharing and doing as a compromised experience	✓	✓	✓	✓
c) <i>"You have to put up with that"</i> – tolerance as caregivers' way of coping with a compromised experience	✓	✓	✓	✓
II) Caring as an experience devoid of social connectedness:				
a) <i>"But I don't think he realises how serious it is"</i> – Caregivers' loneliness due their loved one's unawareness of the extent of their dementia	✓	✓	✓	✓
b) <i>"It's full time ... day and night job"</i> – caring dominates and interrupts everyday life and relationships	✓	✓	✓	✓
III) Caring as an experience of depletion:				
a) <i>"It's difficult"</i> – an ongoing experience of frustration and dissatisfaction	✓	✓	✓	✓
b) <i>"It gets a bit tiring"</i> – adverse effects of caring on health	✗	✓	✗	✓
c) <i>"Thinking for him as well as for me"</i> – The continuous monitoring/ managing of the caring situation can be overwhelming	✓	✓	✓	✓

Table 3: Caregivers’ experiences of participation in a facilitated carers’ creative art leisure group in a Healthy Ageing Café

Themes/descriptor and sub themes:	Bob	Doreen	Maggie	Lydia
1. “It felt good doing art work” – An accumulation of positive influences of art-making on mood and identity	✓	✓	✓	✓
a) <i>“I hadn’t thought I can do anything like that”</i> - The confidence building qualities of art making towards a transformed sense of self	✓	✓	✓	✓
b) <i>“Doing something which I thought I had done well”</i> – The positive experience of pride and achievement	✓	✓	✓	✓
c) <i>“Get the creative side coming out”</i> - An opportunity for spontaneous self-expression	✓	✓	✓	✓
2. “Enjoying being together” –group interaction motivates participation	✓	✓	✓	✓
a) <i>“It was collective”</i> - Finding camaraderie in a shared collective experience	✓	✓	✓	✓
b) <i>“Encourage each other along”</i> - The mutual beneficial effect of reciprocity which sustained participation	✓	✓	✓	✓
c) <i>“It was the atmosphere”</i> – the multi-faceted role of the facilitators in creating a conducive environment.	✓	✓	✓	✓
3. “It was a sort of a respite thing” – The carers’ art group as a space of freedom to allow carers to do their “own things”	✓	✓	✓	✓

4. <i>“Easier to care”</i> – influence of the creative arts groups on care-giving	✓	✘	✓	✓
5. <i>“Wasn’t long enough”</i> –Limitations of the carers’ art programme	✘	✓	✓	✓