Our Day Out: The perspective of carers

1. The Context of Care

It is well known that there are increasing numbers of people living with dementia in all parts of the world and that in the UK, many are living in the community (not solely in institutional care). Similarly, there are also increasing numbers of people (spouses, partners, family members and friends) who are carers, in those same communities. Some basic statistics outlining the situation of carers of people with dementia in the UK are included in the following table:

• There are c.700,000 informal carers for the 850,000 people with dementia in the UK.
• Women are 2.3 times more likely to provide care for someone with dementia for over 5 years.
• 60-70% of carers for people with dementia are women.
• 48.4% of carers have a long-standing illness or disability.

(Alzheimer's Research UK, 2019)

The tendency for women to be carers was noted anecdotally in our interviews by the one man who was a primary care-giver:

> *I'm the only man caring for anyone. There are women with dementia but their husbands have died and they're on their own.* (C03).

In a profound sense, and irrespective of gender, the partners of people with dementia are also living with the condition (Nuffield Council on Bioethics, 2009). Just as it has been recognised within disability studies that having a physical (or mental) impairment must be understood within a relational context – in terms of how it affects a person's friends and family, so too dementia must be appreciated as it is relational (Hughes, 2014, Killick, 2013). As noted elsewhere:

> '…people live their lives relationally. In every state, including the wealthiest, informal carers provide the majority of assistance.' (Shakespeare, Zeilig & Mittler, 2017)

Therefore, the experiences of the family and other informal carers must be appreciated and their needs should also be supported. As is stated by Alzheimer's Research UK:
'Caring for someone with dementia puts a huge strain on the carer's physical and mental health.' This observation is echoed in the vast majority of the most recent research examining the role of carers. This literature further notes that whilst caring per se is stressful, caring for people with dementia is especially burdensome (Smith et al, 2018).

Caring comprises a multiplicity of tasks, including hands-on practical care and also: anticipating future support needs, monitoring and supervising, preserving the individual's sense of self and helping an individual develop new and valued roles (Farina et al, 2017: 573). The role of carer, therefore involves a heavy mental and emotional load as well as pragmatic and material demands. Caring for someone with a dementia may be further complicated by resistance to care, agitation and sometimes a lack of insight by the person with dementia into their own needs (Farina, as above). Often, the carers for someone with dementia are old and have health needs themselves

In direct acknowledgement of the stresses associated with this role (and no doubt also due to a recognition that economies depend on the role of 'informal' carers), many countries have developed national strategies to support carers. Thus, for instance in the UK and in other European countries such as France, Italy and the Netherlands there are now national dementia strategies that explicitly and centrally foreground the role of the carer. Other recent innovations in the UK include: 'toolkits' aimed at helping carers and ring-fenced funding (Care Act, 2014) so that carers can have breaks. There have also been psychological interventions for carers such as counselling and psychoeducational training (Dickinson et al, 2017). Nevertheless, progress remains slow and the daily needs and struggles of carers, are still mostly overlooked. Some research suggests that if carers' quality of life and psychological well-being is to be improved, then more targeted interventions are required (Morris et al, 2018). Nonetheless, the growth of these initiatives demonstrates an awareness of the role that could be fulfilled if there was an infrastructure to support carers as well as those with dementia, together (Smith et al, 2018:188).

These sociodemographic factors constitute the wider context for the ODO sessions. A context that is characterised by an ageing population and rising numbers of people with dementia. In addition, the current socio-political climate is defining, in that it increasingly devolves care away from a collective responsibility to the private or familial realm. Consequently, the role of carers – who are relied on by the state to provide the mainstay of support for people with dementia, is crucial. As Farina et al (2017) note:

> 'Without the work of family carers, the formal care system would collapse: supporting family carers is therefore a national and international policy priority.' (573).

This is the background then, for our interest in the extent to which the ODO sessions were able to positively impact the lives of carers (as well as people with dementia). A further contextual dimension includes the interest in and understanding about the role of the arts for people with dementia and their carers (Camic, Zeilig & Crutch, 2018, Osman, Tischler & Schneider, 2016, Zeilig et al, 2015). Increasing interest in the role of the arts in dementia care parallels wider academic and policy discourses in the cultural sector around everyday participation and cultural value, with an emphasis on social inclusion and understanding the social relations of participation and production, as discussed elsewhere (Zeilig et al, 2018, Robertson & McCall, 2018).

The Our Day Out sessions are primarily designed to be enjoyable, art-based and creative activities. These sessions were structured with the intention of including carers equally alongside their partners, in the understanding that both members of a couple may have a need for the activities. The sessions are leisure activities. However, it should be noted that the emphasis on 'leisure' is not to imply a frivolous, passe-temps. On the contrary, research has established the contribution of leisure to well-being:

> '…leisure pursuits can promote both social and mental well-being' (Innes, Page & Cutler, 2016)

and the extent to which dementia transfigures the relationship of leisure to well-being, for a couple, is increasingly recognised. The ability for people with dementia and their carers to pursue leisure activities together has been associated with the maintenance of quality of life for both partners. In addition, the connection of leisure activities to sense of identity and self-worth has been demonstrated (Genoe & Dupuis, 2014). Leisure has even been associated with an ability to resist negative and stigmatising stereotypes of dementia, whilst also building confidence to live with the condition (Genoe, 2010, Innes et al, 2016). In other scholarship, the link between improved confidence and well-being for people with dementia has been established (Camic – CWS wellbeing scale). It is noteworthy that in the three interviews with carers that are reported on below, a sense of increased confidence is reflected on, for both themselves and for their partners with dementia.

2. THEMES from Carer's Interviews

The three interviews took place in a range of locations in Norfolk, two were in the interviewee's home and one in a local café. Ethical protocol was followed and consent obtained by each interviewee[1]. The interviews were all semi-structured and followed the same schedule, although this was used flexibly where necessary, and a conversational style was adopted. In all cases, the questions were directed at the carer but their spouse was included whenever relevant. Photographs of particular sessions were used as prompts and were also an effective means of including the spouse with dementia. Questions focussed on the carer's perception of their role, including whether carer was considered an appropriate term and whether the ODO sessions had effected this in any way. The views of respondents about the role of the

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[1] Interviews have been anonymised – Sonia: Sylvie, Maggie: Marion and Tony: Bill (all real names should be removed from the final report!).

arts in their lives and whether ODO sessions had increased their sense of creativity were also sought. These interviews were all transcribed, coded and analysed thematically. Themes were developed both before the analysis, based on the project aims, and during analysis to pick up new and emerging themes (Bryman, 2008). The main themes that emerged are discussed below. Due to the very small sample size, this cannot be assumed to be representative of the views of carers from ODO in general, though they do support the quantitative and qualitive data collected from carer participants. Nevertheless, some interesting insights emerged from this detailed analysis of the interviews and it is striking that these overlap closely with other work on the impact of community support interventions on carers of people with dementia. For example: recent reviews stress the importance for carers of being listened to, of the emotional boost that community support groups can give, of feeling connected and the value of having friends (Farina et al, 2017, Smith et al, 2018). In addition, the carers interviewed about the ODO sessions also emphasised the significance of being able to have ‘a laugh’.

2.1 Wife, carer, partner…? identities

At the beginning of each interview, a question was asked about whether the term ‘carer’ was felt to be appropriate or whether another word such as ‘partner’ or companion was more suitable. In part this questioning was prompted by recent scholarship that critiques the widely accepted and mostly unquestioned use of ‘carer’. According to some researchers (Molyneaux et al, 2011) ‘carer’ is ineffective because it fails to give a valid description of the relationship between ‘carers’ and those for whom they care. Moreover, it is argued that it tends to polarise the individual cared for, from the ‘carer’ when more often couples work together.

Our interest in querying the term with interviewees was therefore in order to start exploring the role that the interviewee felt that they now had in relation to their husband / wife. However, we were also curious to elucidate what the business of caring meant for these individuals who were long-term carers; whether emotional or functional tasks were prioritised or considered equally. This in turn led on to discussions about whether and to what extent the ODO sessions affected peoples’ ability to care.

The identity of carer was regarded, by one woman - Maggie, as being an ‘extra’ role, one that involves additional tasks:

> *Well I think as a wife, you just do different things, but when you're a carer, you've got extra things to do. Because they can't do it theirself. Where anything, repairing something, you've got to do yourself, as well* (Maggie)

For Maggie, being a wife seems to imply doing ‘different’ things and for her the role of carer is entirely connected with a variety of tasks that you have to ‘do’ for someone else and also for yourself.

> *Well like getting his teeth out to put in his beaker to soak, I have to bath him, because he's got psoriasis. I have to get his clothes all out ... oh, he wakes up in the night, I've got put a little light on, because I'm worried he's going the wrong way to the toilet. All that goes on, every night.* (Maggie)

This thorough account of the chores that she has to perform, every night, illustrates the responsibility that Maggie feels as carer. It outlines her immersion in the intimate details of her husband’s life (taking his teeth out) which previously she would not have been involved with – and also perhaps indicates why she feels that being a ‘carer’ is qualitatively different from being a ‘wife’.

For Sonia, the word ‘carer’ was, once she paused to consider it, slightly amiss:

> *when you're married to somebody, a carer is somebody that gets, it reminds me of somebody that gets paid for what they do otherwise I think, I don’t know what you'd call us really.*

There is, for her, a certain anomie connected with her role (is it part of being married to someone or a separate, paid job?) that can be slightly disorientating. Sonia goes on to explain how she is now in control of nearly every aspect of their lives

> *'..now it's come to the point where you've got to control the money, pay out for everything and make sure the bills and that get paid and do the cooking and things like that. Well everything really because A's memory just can't remember…'*

This necessary assumption of control means that her relationship with her husband is unbalanced. In addition, Sonia states that because she is responsible for nearly all domestic affairs that she no longer has *'much freedom'*.

For Tony, the word 'carer' seemed apt:

> *I mean, a carer, it's what I do, I care. I care what happens and I try to make sure she's safe and well, and as good a life as she can. And I think that's caring.* (Tony)

Here, he prioritises the emotional aspect of caring – the need to make sure his wife is safe and beyond that, that she is having a 'good life'. Tony went to reflect that the term 'companion' is complicated: 'you aren't able to be a companion to someone that can't really know what's going on a lot of the time.' This reflection was interrupted by his wife and the following exchange ensued:

> *RES2: But you're my husband, aren't you, darling?*
>
> *RES1: I'm your, I'm everything, and you're everything to me. ... I don't think, I don't want respite, because I can't be away from Txx. I've got to be, it's as much for me to be with her, as for her to be with me.*

The interdependency and profound love between this husband and wife was evident throughout the interview, although Tony also emphasised the daily chores that mark his life with Txx:

> *'I do the cooking, the shopping, the accounts, the garden, cleaning.'*

Overall, it seems that all those interviewed did feel that they were in a number of clearly identifiable ways performing 'caring' tasks for their spouses and that to varying extents this represented a new role, something 'different' than being a wife or husband. Although each interviewee mentioned the restrictions that caring involved, there was no sense of resentment expressed.

2.2 Laughter, a 'break', connection - Communities

The opportunity to laugh and have fun was considered a centrally important feature of the sessions, by the carers that were interviewed. For instance, the fun of the belly dancing sessions was noted by both Maggie and Sonia:

> *'I think the belly dancing, that's quite fun, we got a good laugh with that, yes.'* (Sonia)

As discussed elsewhere (cf: CAE work on interviews with people with dementia) there is increasing understanding about the value of playfulness and fun for those with dementia, but there has been less focus on the need for carers to also experience the relief of laughter. The sense of connection that can be generated in ODO sessions through laughter, is neatly captured in a recollection that Sonia shared:

> *'…his wife … looks across at me and she goes it's funny and we both have a good laugh about it yes.'*

It is noteworthy, the ODO artists stressed the importance of ensuring liberal doses of fun and friendliness in the sessions that they were leading:

> The artists in the focus group (and also in their reflection logs) all emphasised the relevance of creating a positive mood and atmosphere both within the sessions (in terms of a friendly, warm and joyful atmosphere) and between participants – as a means of encouraging engagement. (analysis of artists' focus group March 2018)

In terms of the experience of the carers who were interviewed, this positivity was clearly achieved and greatly appreciated. Indeed, the enjoyment of being able to joke and banter with their spouses and also with others in the same situation was valued by all the carers.

This sense of fun seemed to help them forge connections and also to experience the ODO sessions as a 'break'. As Maggie commented:

> *I thoroughly enjoyed going. It's a little break for me. To me, it's a break. The ones who are in charge are very good with him, with his dementia, and you know, they know, and they're very good, and I can enjoy myself, without worrying* (Maggie)

According to Maggie, the ODO sessions also function as several hours of respite from the day-to-day routines and from 'worrying'. They represent a supported break for some carers, which allows them the freedom to relax and joke with others. Although the other carers did not explicitly mention idea that the sessions were a 'break', they did discuss the enjoyment of not simply 'sitting at home' (Tony) and of 'doing something different' and specifically something that 'livens you up' (Sonia).

The ODO sessions helped the carers who were interviewed find friendships and so feel part of a wider social group. This group may also be understood as a small community, one that centres around arts activities and comprises people who are understanding and accepting. So, Maggie commented that during the sessions '*they accept us as we are'* – that if her husband (and consequently herself) is having a bad day, they will still be accepted in the ODO sessions. Maggie further elaborated that:

> *'…it's nice to get out, and socialise with somebody who knows what I'm saying'.* (Maggie)

Similarly, Tony discussed how the sessions provide an opportunity to talk to people and Sonia observed:

> *'…it's just when you go there you know that you're not alone and there's other women and men in the same situation as yourself but also there's other women and men that are carers that have problems of their own health wise.'*

Whilst the focus of the session may be on making music together or dancing, there is nonetheless a commonality of experience amongst the participants. The carers all reflected on this (as is evident from the quotes above) as something that helped alleviate their sense of being alone. As noted by others (Smith et al, 2018) being part of a community can help build carers' resilience and ability to identify positive aspects of their role and thus to manage it better (Morris et al, 2018).

As a result of this combination of factors (the sense of community, an ability to have fun and feel relaxed) the carers all experienced the sessions as times which were as much for them as for their spouse, and as extremely pleasurable:

> *It's just a pleasurable thing to do because of social interactiveness. It's just a nice thing to do and to be able to go out. And the days out are nice because the group, going out together, it's really good, you know. It helps to, well, produce a little bit of pleasure.* (Tony)

2.3 Independence, continuity and feeling special: Engagement

The ODO activities are designed for older couples and are inclusive of people with dementia. Care is taken to ensure that venues are accessible and that people are able to get to and from the sessions: this is not an insignificant feature, given that take place in rural locations in Norfolk. The accessibility combined with artist led activities that are creative and inclusive, contribute to carers' noting that the sessions help them feel independent. As Maggie said, the activities mean that they are not wholly reliant on their family to entertain or look after them:

> *'Yes, because otherwise you're just reliant on your family to break the monotony for you and take you off out somewhere but with this we get our days out and we also get the day out at the dementia place and it's a complete day to us because we stay for dinner and then we have the afternoon sessions with the arts people.'*

Similarly, Sonia commented that the ODO sessions, especially the days out, provide an important opportunity for doing something, independently as a couple:

> *'…because the position we're in now, we can't get out as much as what we used to can we?'*

In all cases, the interviewees expressed their appreciation that sessions involved their partners, who can still participate, thus maintaining their ability to retain some independence. As Sonia remarked, the artists who lead sessions *'treat Axx as one of the rest of us..*'.

Just as a sense of independence is generated by ODO sessions, so too is continuity. The sessions allow couples the opportunity to continue being a couple, 'doing' something together and being seen and acknowledged in a more public space as a 'couple'. This is valuable because it gives spouses a sense of continuity – that their lives as a partnership remain meaningful. Thus, Maggie noted how her husband had always enjoyed being active and the group gave him an opportunity to continue being so and Sonia said that she and her husband had always led an engaged and active life. Similarly, Tony outlined the extreme isolation that dementia often involves and the inevitable discontinuities that the illness can inflict on someone:

> *This is the horrible thing for Txx, socially. She hasn't got, she used to have fantastic input, she had a really good top job in London. But she doesn't start a conversation, or even take part in a conversation.*

In contrast, the ODO sessions restore some ability to socialise and therefore a much-needed continuity in terms of activity and identity.

The role of the co-ordinators who individually welcome each person and the knowledge that the session has been thought through and planned – that people are '*interested'* (as noted by Maggie) specifically in how you are, is particularly important. As Tony mentioned, the facilitators 'make you feel comfortable, immediately'. This is in contrast to the stories (told by almost every interviewee) about how GPs and other services seem to take little interest in the particular circumstances of either the carer or the person that they are caring for. This was stressed by Maggie who towards the end of our interview added:

> *'Yes, another thing is they do make you feel special.*'

She went on to elaborate that the ODO sessions are one place where neither she nor her husband feel ignored:

> '*..they don't ignore you, you don't get ignored they just make you feel that you're welcome there and they're interested in you and make you feel special yes*.'

Concluding thoughts

There was relatively little reflection, despite prompts, about the specific role of the arts / artists. Where the music and dance was discussed it was noted that they offered something 'different' and a 'variety' of experiences. Nevertheless, the ways in which artists used movement with music to include people with dementia was appreciated

> *'..they go, "come on V, what movement do you want?" And he might just do ... go like that, and we'll go up, and they go, "that's a good one, yeah, we're all doing that". So, we all do it. So, you're not feeling silly.'* (Maggie).

Above all, being part of an empathic and nurturing group was regarded as the real value of the sessions:

> *'…the arts thing is really somewhere to go, it's somewhere to go and socialise and something different than what we normally do isn't it?.'* (Maggie)

However, Sonia did mention that her husband (who is living with dementia) had been inspired by the sessions to do more painting and Tony also observed that he was more inclined to play music at home nowadays:

> *'I just take it into my head to sit at the piano and I'll play tunes. Half of them, you wouldn't know, I suppose, because I go back to wartime stuff. ... And immediately, I could hear Txx singing away in the bedroom, wherever she was.'*

Although the role of the arts in the ODO sessions was not an overt focus for the carers, as is argued elsewhere (in analysis of CAE sessions, August 2017 and also in published work: Zeilig et al 2014, 2015,

2018) the arts create a means of communicating and connecting that privilege a playfulness and have a unique value for people with dementia and their carers.

In the middle of one interview, in which we were exploring a carer's views about the different ways in which ODO sessions had affected her life (to the extent that they had), her husband who had seemed disinterested in our conversation loudly injected with the comment '*you only live once so go for it*'. He went on to explain that '*it's no good just sitting there!*'. This observation aptly captures the courageous spirit of all those who were interviewed - who despite the difficulties of living with dementia, were prepared to take part in new activities and to continue engaging with life.

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