**A socially-prescribed community service for people living with dementia and family carers and its long-term effects on well-being**

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**Abstract**

**Background:** Support services for people with dementia are variable depending on the area or town they live. People with dementia and family carers can often get very little support after a diagnosis. Services might not be suitable or they may not be aware of the service in the first place. The aim of this study was to evaluate a socially-prescribed community service provided to people with dementia and family carers offering physical and mental activities.

**Methods:** People with dementia and family carers were recruited from a community centre in the North West of England to complete in this study. Participants provided demographic information and completed the Short Warwick-Edinburgh Mental Well-being Scale at baseline, and after 3 and 6 months. Postcode data was used to generate an Index of Multiple Deprivation (IMD) score for information on participants’ socio-economic background. Data were analysed using paired samples t-tests to compare well-being scores between baseline and follow-up assessments.

**Results:** 25 people with dementia (n=14) and family carers (n=11) participated in the service. Visits ranged from 1 to 36, with 22 and 15 participants completing the 3- and 6-month follow-up, respectively. Some reasons for discontinuation were lack of transport and other commitments. Most participants lived in some of the most disadvantaged neighbourhoods. Compared to baseline, well-being was significantly higher at both follow-ups.

**Conclusions:** This is one of the first studies reporting the benefits of a social prescribing service in dementia. Future implementation work needs to design an implementation plan so that the service can be implemented in other community centres across the country.

**Keywords:** social activities, social prescribing, deprivation, well-being

**What is known about this topic:**

- Social engagement is linked to improved quality of life.

- Accessing joint activities for people with dementia and carers can be beneficial for both.

- There is limited research on social prescribing and its effects in dementia.

**What this paper adds:**

- First evidence on a socially-prescribed community service for dementia.

- Engaging in socially prescribed community-based activity is linked to increased well-being.

- There needs to be a greater focus on social prescribing by clinical professionals.

**Introduction**

Dementia affects an estimated 50 million people worldwide (ADI, 2016), with over 850,000 people living with dementia (PLWD) in the UK alone (Prince et al., 2014). However, dementia does not only affect the person living with the condition, but also their immediate family and friends. Indeed, in the UK, family carers carry the largest costs in terms of providing unpaid care, estimated at over £11 billion each year alone (Prince et al., 2014).

 Whilst dementia is a neurodegenerative condition, and medication can only delay symptom deterioration for some subtypes, there are other ways in which to support PLWD to experience a good quality of life (QoL) and to support them to stay independent at home for longer, something PLWD strive for (Rapaport et al., 2020). This is important as QoL is negatively affected by dementia symptomatology, including difficulties with everyday activities (Giebel et al., 2017) and behavioural difficulties (Buckley et al., 2012). Evidence shows however that engaging in social activities and maintaining an active social life is associated with improved QoL (Giebel et al., 2016), suggesting the clear value of staying socially active. Indeed, engaging in social activities in middle age has also been found to reduce the risk of developing dementia (Sommerlad et al., 2019), whilst community cultural engagement was found to be associated with reduced risk of developing dementia in a recent national registry-based study (Fancourt et al., 2020).

 Considering the importance of staying socially active in dementia, there is a small yet burgeoning evidence base on the benefits of various types of social activities on the well-being of those living with dementia, as well as family carers. Museums- and arts-based programmes are receiving increased interest in the literature and have shown positive effects on the well-being of PLWD (Belver et al., 2018; Camic et al., 2014; Roe et al., 2016). For example, attending an art gallery over eight weeks resulted in positive changes to well-being and social impact (Camic et al., 2014). Johnson and colleagues (2017) reported positive impacts on the well-being of PLWD and family carers resulting from museums-based object handling activities, which corroborates the recommendations of using museums and art galleries as partners in public health interventions in general (Camic & Chatterjee, 2013).

Engaging in (social) physical activities has also been linked to having a positive effect on well-being in PLWD (Brett et al., 2016; Kelson et al., 2017), as well as showing positive effects on cognition and levels of independence (Cheng et al., 2014; Potter et al., 2011). In a recent systematic review, Brett and colleagues (2016) for example showed that engaging in physical activities improved well-being in nursing home residents with dementia. However, a previous systematic review found mixed evidence on the effects of physical activities on well-being in PLWD in and out of care homes (Potter et al., 2011). Exercise releases endorphins and generally provides a positive feeling afterwards (Mikkelsen et al., 2017), so by merging this with social groups and enabling people to meet one another is likely to have a longer lasting effect on well-being than one-off exercises.

 One way that aims to improve access to social activities in the community, be they of physical or arts and crafts nature for example, is via social prescribing. In the past few years, social prescribing has been pushed as an alternative or add-on to medical and psychological treatments where possible. In particular, social prescribing involves a clinician, often a General Practitioner (GP), prescribing specific social activities to a patient to improve their well-being (Polley et al., 2017). The patient is then referred to a link worker, who will assess jointly with the patient what types of activities they would like to engage with, as activities need to be tailored to the individual. Whilst there is evidence showing the benefits of social activity engagement on well-being in dementia (Belver et al., 2018; Camic et al., 2011), there is little to no research specifically on social prescribing in this population or older adults, with some research from other neurological conditions (Simpson et al., 2020). Thomson and colleagues (2018) for example reported positive effects on the psychological well-being of older adults from a socially prescribed museum activity. Camic et al. (2011) reported that a singing together group in 10 PLWD resulted in relatively stable QoL, but their pilot evaluation was based on very small numbers. In light of increased rates of developing dementia in spouses of loved ones with dementia (Norton et al., 2010), it is pertinent to focus on strategies to improve the well-being of family carers to reduce this potential risk. Considering the sparsity of research into the effects of social prescribing in dementia and family caregiving, there is a clear gap in the evidence base which needs to be addressed to ensure that the push for social prescribing is justified and benefits everyone.

The aim of this study was to evaluate a socially-prescribed community service for PLWD and family carers. Whilst social prescribing is receiving a great deal of attention at the moment, for example as prioritised in the NHS Long Term Plan (2019), to date there is little evidence showcasing the benefits of socially prescribed activities and services, particularly for dementia. Based on the limited evidence for social prescribing, and based on some existing evidence on the link between social activities and well-being, we hypothesised that this pilot socially-prescribed community service would be associated with positive changes on well-being. Findings of this study will help to start filling the current gap in the literature, and will provide important insights for future research and implementation in the field.

**Methods**

**Participants and recruitment**

Participants were people with a diagnosis of dementia (any subtype and age) and their family carer. PLWD and family carers were referred to the service by the psychiatrist at the memory clinics and GPs. If they were very unwell from physical or mental health point of view to participate in these classes, they would not be referred. Some people self-referred by finding out about the social prescribing services and the classes via word of mouth and social media.

**The service**

The local community and leisure centre hosts weekly ‘Happy and Healthy’ classes, which comprise physical and mental well-being exercises. The first class started in January 2019, and classes are ongoing weekly. Each class lasts 60 minutes in total, including a variation of low-impact exercises, local walks, Tai Chi, relaxation techniques, mindfulness, and games, which varies from week to week. The whole group did the activities as a group and there were some changes to activities on various days. Each weekly session is delivered by two community centre advisers. PLWD pay a nominal amount of £3.35 to attend each session, and family carers can attend for free with a carer’s pass for 12 months. In addition to the ‘Happy and Healthy’ classes, people with dementia and family carers are also invited to attend other classes on offer at the leisure centre, including ‘quiet hours’ in the gym and also some dedicated ‘quiet hours’ embedded in the swimming timetable for those living with dementia. For those who wanted additional exercise classes we advised those who attended the class what other classes were suitable to attend. This included Low Impact Exercise classes and some water-based exercise classes.

This service is a joint collaboration between the local NHS Trust and clinical settings, as well as the local council, clinical commissioning group, third sector organisations and unpaid dementia carers. Dementia care navigators support the well-being of PLWD and carers and signpost PLWD to various well-being services, including the ‘Happy and Healthy’ classes.

**Data collection**

Basic demographic data (age, gender, ethnicity, type of dementia, family carer’s relationship to person with dementia) as well as postcode data are collected at the beginning of the first session. Postcode data was then translated into an Index of Multiple Deprivation (IMD) quintile to understand the level of deprivation of the neighbourhood participants lived in. Neighbourhoods in Quintile ‘1’ belong to the most disadvantaged neighbourhoods across England, with Quintile ‘5’ referring to the least disadvantaged neighbourhoods. The IMD measures seven domains of deprivation, including income, employment, education, health, crime, barriers to housing and services, and living environment.

Well-being was measured using the Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS) (Stewart-Brown et al., 2009) at baseline, 3-months follow-up, and 6-month follow-up. The SWEMWBS measures well-being by asking 7 of the original 14-question version, and has shown to have adequate internal consistency and reliability (Haver et al., 2015), with almost perfect agreement between SWEMWBS and the WEMWBS as indicated via weighted kappa statistics (0.79-0.85) (Fat et al., 2017). Statements include “I’ve been feeling optimistic about the future” and “I’ve been able to make up my own mind about things”. Each item can be scored on a range from ‘1’ to ‘5’, with the total score raging from ‘7’ to ‘35’. A higher score indicates higher levels of well-being.

Data were collected as part of the ongoing evaluation of this new social prescribing service for PwD and family carers, provided by an NHS Trust. Therefore, no ethical approval was required.

**Data analysis**

Data were analysed using SPSS 25. Frequency analysis was used to analyse demographic characteristics. Paired samples t-tests were used to compare SWEMWBS scores between baseline and 3-month and 6-month follow-ups. Bivariate correlation analysis was used to explore the association between number of visits and score variations between baseline and 3-month assessment, and baseline and 6-month assessment.

**Results**

By January 2020, a total of 25 people with dementia (n=14) and family carers (n=11) had participated in the socially prescribed classes. PLWD were mostly male (64.3%), accompanied by either a spouse or a child (71.4%). Family carers were mostly female (63.6%), spouses (90.9%). Participants were on average 74 (+/- 8) years old [Range 57-90]. The majority of participants lived in some of the most disadvantaged neighbourhoods as measured by the IMD quintile, with 84 percent living in Quintile 1 and 2 neighbourhoods. Participants had a median of eight visits to the classes, which ranged from 1 to 36 visits.

**Baseline and follow-up assessments of well-being**

All 25 participants completed baseline measures of the SWEMWBS, with 22 completing the 3-month follow-up assessment and 15 participants completing the 6-month follow-up assessment. At the point of data cut off, four people had not been to the classes for six months, which is why they were missing. Paired samples t-tests showed that between baseline (Mean: 24.7 +/-4.2) and 3-month follow-up (Mean=26.3 +/-4.1), participants showed a significant improvement in levels of well-being [t(21)=-4.168, p=.000]. Only one participant scored 1 point less on the SWEMWBS at the 3-month follow-up, with eight participants reporting no changes. 59.1 percent of participants (n=13) reported a positive change in their follow-up assessment.

Comparing scores between baseline (Mean=24.8 +/-4.6) and 6-month follow-up (Mean=27.0 +/-4.4) of the 15 participants who completed the last follow-up, paired samples t-tests showed that people with dementia and family carers scored significantly higher at the 6-month assessment [t(14)=-4.102, p=.001]. One participant scored 1 point less at the 6-month follow-up, with two participants measuring no changes. 80 percent of participants (n=13) measured positive changes on the SWEMWBS.

The number of visits was not found to be significantly correlated with variations in scores on the SWEMWBS at 3- and 6-month follow-up (p=.679; p=.941).

Figure 1 shows the mean scores on the SWEMWBS at baseline, 3-month and 6-month follow-up for PLWD and family carers separately. For both participant groups, well-being scores increased over the follow-ups compared to baseline.

**[insert here Figure 1]**

**Discussion**

This is one of the first studies exploring the effects of a socially-prescribed community service for PLWD and family carers in the community. Supporting our hypothesis, this pilot study showed that engaging in the ‘Healthy and Happy’ classes was found to be linked to improvements in well-being over a 3- and 6-month period.

 Overall, participants engaging in these physical and mental exercise classes were found to show improvements in their levels of well-being. This corroborates and complements previous evidence on social physical activities, such as a neighbourhood walking group for people with young-onset dementia (YOD) (Phinney et al., 2016). Participating in a neighbourhood walking group with other people living with YOD generated a sense of belonging and had positive effects on attendees. Also, implementing socially-prescribed classes addressing physical and mental activities such as the ‘Healthy and Happy’ classes seem to be a more easily implementable and deliverable community-based support service than some other, more extensive, multimodal interventions (i.e. Burgener et al., 2008). It is important to note though that no relationship between engaging in this socially prescribed activity and well-being could be assessed. This is because well-being was only measured in those people who took part in the classes, and not in PLWD and family carers who received no such socially-prescribed activity. Furthermore, due to the relatively small samples of PLWD and carers individually, it was not feasible to statistically analyse both groups separately. However, these first findings are promising and a larger implementation of the service, collecting more data, will enable separate analysis.

 However, the present study provided longitudinal measures of well-being, and few previous studies have measured the effects of a routine community-provided social activity on well-being. A recent longitudinal investigation of a visual arts programme for PLWD showed that proxy-rated QoL improved from baseline to 3-month follow-up, yet not when self-reported (Windle et al., 2018). Whilst this social activity programme similarly showcases improvements in well-being over time, the programme was a specifically set up 12-week programme, and thus not enabling people to drop in and out when suitable, such as in the ‘Healthy and Happy’ classes. Moreover, our study explored longitudinal effects over a longer time period as well, showing the long-term effects of the classes on the attendees’ levels of well-being.

 Engaging in a social activity can also potentially reduce social isolation. Whilst people were referred to this service due to their dementia or due to caring for a loved one with dementia, social prescribing can be relevant for a number of reasons, including addressing depression and feelings of isolation (Chatterjee et al., 2018). Indeed, social isolation is common in older people and found to underpin loneliness (Shankar et al., 2017), so that enabling services such as the ‘Healthy and Happy’ classes are a vital component of community social care provision to address loneliness and enable older adults (with dementia) and those caring for loved ones to meet and interact with others.

Attendance varied from 1 to up to 36 visits in the time period assessed, and a small attrition rate was found from baseline to 3-month, and to 6-month follow-up. With the classes still ongoing, some participants have their first visit dating back less than six months, so that no 6-month follow-up data existed at the time of analysis. Attrition is commonly observed in studies and activities that last over a longer period of time (i.e. Cooper et al., 2016; Livingston et al., 2013). For the ‘Healthy and Happy’ classes, most people reported difficulties using transport to the location and other existing or new commitments as some of the main reasons for discontinuation. Considering that most attendees resided in some of the most disadvantaged neighbourhoods in the country, as measured by the Index of Multiple Deprivation, many attendees are likely to have been relying on public transport. However, public transport across this Northern town can be limited at times, with previous evidence supporting the notion of transport being a major issue in accessing dementia care services (Innes et al., 2005; Morgan et al., 2002). One way to overcome this difficulty and enable wider, more equal access, would be to provide the service in different community centres across the town. Current work is looking at expanding the service wider, also across the region. Another option may be to provide cheap or indeed free communal transport to and from the site.

**Limitations**

This is a pilot evaluation of a socially-prescribed physical and mental exercise class for PLWD and family carers, and therefore not based on a large cohort of participants. However, based on the sample significant longitudinal changes in levels of well-being were already observed, suggesting the need for and benefits of a wider implementation of this service. Paired samples t-tests are feasible with much smaller sample sizes than the one in our study (de Winter, 2013). It is to be noted that no assumptions can be made on the causality between attending the classes and levels of well-being, as this was not a randomised controlled trial. Also, this study did not include PLWD and family carers who did not attend the classes, so there is no control group. The control in this study is the comparison of follow-up with baseline assessments. Nevertheless, other published research in the field looking at engaging in social activities (without the social prescribing focus) equally reported benefits of specific social activities on well-being (i.e. Roe et al., 2016) without being able to draw causal conclusions about their relationship.

**Conclusions**

This is one of the first studies to report on the benefits of a socially-prescribed physical and mental exercise class for PLWD and family carers, showing longitudinal benefits of engaging in the classes on well-being. Considering the sparsity of evidence on the effects of social prescribing for various population groups, including dementia, this pilot study starts filling a large gap in the evidence base to date and findings support the recent push for social prescribing, as outlined in the NHS Long Term Plan (2019). One of the next steps will be to draw up an implementation plan to aid wider implementation of the service across the country.

**Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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**Figure 1. Mean well-being scores at baseline and follow-ups for people with dementia and carers**