

**The impact of volunteering on the volunteer: findings from a peer support programme for family carers of people with dementia**

Georgina Charlesworth MA MPhil ClinPsyD PhD<sup>1,2</sup>, James B. Sinclair MA MRes<sup>1,2</sup>, Alice Brooks BSc MSc DClInPsy<sup>1</sup>, Theresa Sullivan BSc<sup>1</sup>, Shaheen Ahmad<sup>3</sup> and Fiona Poland BAEcon MAEcon PhD<sup>4</sup>.

<sup>1</sup>Research and Development Department, North East London NHS Foundation Trust, London.

<sup>2</sup>Research Department of Clinical, Educational, and Health Psychology, University College London, London.

<sup>3</sup>Dementia Advisory Service, Age Concern Havering, Regarth Avenue, Romford, UK.

<sup>4</sup>School of Allied Health Professions, University of East Anglia, Norwich, UK

Word Count: 4968 excluding abstract, acknowledgements, references and tables

Corresponding author:

Dr Georgina Charlesworth

[g.charlesworth@ucl.ac.uk](mailto:g.charlesworth@ucl.ac.uk)

Research Department of Clinical, Educational and Health Psychology

University College London

1-19 Torrington Place

London

WC1E 7HB

## **Acknowledgements**

- This article presents independent research funded by the National Institute for Health Research (Programme Grant Reference RP-PG-0606-1083. Support at Home – Interventions to Enhance Life in Dementia (SHIELD)). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.
- The SHIELD Programme grant holders were Professor Martin Orrell (UCL/ NELFT), Dr Georgina Charlesworth (UCL/ NELFT), Professor Bob Woods (Bangor), Professor David Challis (Manchester), Professor Ian Russell (Swansea), Professor Esme Moniz-Cook (Hull) and Professor Martin Knapp (LSE).
- For the Carer Supporter Programme, Site Principal Investigators were Georgina Charlesworth (North East London NHS Foundation Trust), Sue Rey (Northamptonshire Healthcare NHS Foundation Trust), Fiona Poland (University of East Anglia for the Norfolk & Waveney Mental Health NHS Foundation Trust site), Margaret Fox (University of East Anglia) and Gwen Bonner (Berkshire Healthcare NHS Foundation Trust). The following voluntary organisations were also involved in the Carer Supporter programme: In North East London; Age Concern Havering, Redbridge Respite Care Association, Carers of Barking and Dagenham, and Waltham Forest Carers Association: In Norfolk; Age UK Norfolk.

The impact of volunteering on the volunteer: findings from a peer support programme  
for family carers of people with dementia

**Abstract**

With an ageing population, there are increasing numbers of experienced family carers who could provide peer support to newer carers in a similar care situation. The aims of this paper are to: 1) use a cross-sectional study design to compare characteristics of volunteers and recipients of a peer support programme for family carers of people with dementia, in terms of demographic background, social networks, and psychological well-being; and 2) use a longitudinal study design to explore the overall impact of the programme on the volunteers in terms of psychological well-being. Data were collected from programmes run in Norfolk, Northamptonshire, Berkshire and four London boroughs between October 2009 and March 2013. The volunteer role entailed empathic listening and encouragement over a 10-month period. Both carer support volunteers ( $N=87$ ) and recipient family carers ( $N=109$ ) provided baseline demographic information. Data on social networks, personal growth, self-efficacy, service use and well-being (SF-12; EuroQol Visual Analogue Scale; Hospital Anxiety and Depression Scale; Control, Autonomy, Self-Realisation, Pleasure-19) were collected prior to the start of the intervention ( $N=43$ ) and at either 3-5 month or 10 month follow-up ( $N=21$ ). Volunteers were more likely than recipients of support to be female and to have cared for a parent / grandparent rather than spouse. Volunteers were also more psychologically well than support recipients in terms of personal growth, depression and perceived well-being. The longitudinal analysis identified

small but significant declines in personal growth and autonomy and a positive correlation between the volunteers' duration of involvement and perceived wellbeing. These findings suggest that carers who volunteer for emotional support roles are resilient and are at little psychological risk from volunteering.

Keywords: Dementia, Carer, Caregiver, Peer Support, Volunteer.

### **What is known about this topic**

- Being a family carer for a person with dementia is associated with burden and psychological morbidities which can extend beyond the duration of the role.
- There are increasing numbers of experienced family carers who are in a unique position of understanding to provide peer support.
- Both positive and negative aspects of volunteering have been identified.

### **What this paper adds**

- Experienced carers who volunteer as peer supporters are more psychologically well in terms of personal growth and mood compared with recipients of the programme.
- Wellness is maintained throughout volunteering notwithstanding slight reductions in autonomy and personal growth.
- Self-rated wellbeing is higher amongst those who volunteer as peer supporters for longer.

## **Introduction**

In the UK an estimated 670,000 family and friends are informal carers for people with dementia living in the community (Alzheimer's Society 2014). This role can be physically and emotionally demanding with carers being more susceptible to poor general health and higher levels of psychological morbidity, depression, stress and burden compared with the general population (Ory *et al.* 1999, Beeson *et al.* 2000, Doran *et al.* 2003, Pinquart & Sörensen 2003, Mahoney *et al.* 2005). Negative effects have also been shown to extend beyond the formal duration of the caring role, with former carers being likely to experience higher levels of depression for several years after the role ends (Robinson-Whelen *et al.* 2001). Nonetheless, some carers choose to support other carers by volunteering in peer support programmes.

### *Social Support*

Family carers of people with dementia with unmet social support needs are at greater risk of role overload, role captivity and subjective stress; having access to a confidant may therefore be an effective way of addressing these risks (Gaugler *et al.* 2004). One approach is through 'mentoring schemes' in which carers are matched with volunteers who might, or might not, have experience of caring. Such a scheme for carers has shown positive effects of decreased anxiety and depression, improved quality of life and increased confidence in caring related tasks (Greenwood & Habibi 2014). However, such benefits are inconsistent; in a large randomised controlled trial of befriending for family carers of people with dementia, no significant benefits were identified (Charlesworth *et al.* 2008).

### *Peer support*

Another strategy for addressing support needs is through peer support in which the both parties have had similar experiences (Hogan *et al.* 2002). Reflecting an ageing population, there are increasing numbers of people with previous or on-going experience caring for a person with dementia, who will be in a unique position of understanding to provide peer support to other dementia carers (Nolan 2001). When the caring role has changed through the person cared for moving into in a care home or dying, the carer may strive for psychological and social reintegration by engaging in new activities, forming new relationships or a new identity (Aneshensel *et al.* 1995). Activities that recall or honour the person they were caring for may be helpful in ascribing a sense of meaning to their experiences and relationship with that person. Many carers are proud of the skills they have acquired in their role and wish to put them to use so as to support others in a similar situation (Yeandle *et al.* 2007). Experienced carers can make a significant contribution to peer support and learning networks, identified as a key objective in the current UK National Dementia Strategy (Department of Health 2009).

A recent systematic review of the impact of volunteering schemes for carers of people with dementia distinguished between peer support, which requires similarity of experiences, and befriending, which does not (Smith & Greenwood 2014). This review identified only three peer support articles, two of which reported the same trial and provided the only quantitative findings. There was no main effect of face-to-face peer support on depression or self-esteem, but support did reduce the depressive effect of disruptive behaviour, suggesting a buffering effect (Pillemer & Suito 2002, Sabir *et al.* 2003).

### *Impact of volunteering on the volunteer*

In the literature on general volunteering, many positive benefits have been attributed to a volunteer role including: confidence and satisfaction (Thoits & Hewitt 2001), self-esteem/ self-growth (Narushima 2005, Low *et al.* 2007), improved physical and mental health (Van Willigen 2000, Lum & Lightfoot 2005, Grimm *et al.* 2007), increased social networks (Rook & Sorkin 2003), and a sense of community (Narushima 2005). To date, there is more research evidence supporting positive aspects of volunteering than negative aspects. This may reflect a research bias focusing more on potential positive gains in outcome measures and the voluntary nature of volunteering: those who do not have a positive experience are more likely to drop out, and their feedback may not be included as a result. However, some negative consequences to volunteering have also been noted, such as stress and burnout (Ross *et al.* 1999, Bakker *et al.* 2007), lack of personal meaning in the role (Narushima 2005), poor relationships formed (Rook & Sorkin 2003), poor training and support (Ross *et al.* 1999), and a perception that efforts are unrecognised (Wilson 2000). These findings are particularly prominent in interpersonal roles that involve working with vulnerable populations, such as the terminally ill (Bakker *et al.* 2007) and HIV/AIDS patients (Ross *et al.* 1999).

There is an ethical obligation to understand more about the impact on volunteers themselves. While little is known about the effectiveness of peer support for dementia carers receiving the support, even less is known about the impact on the volunteers.

The aims of this study are:

- 1) To investigate the demographic, social and psychological characteristics of those volunteering in a peer support programme and how they compare to the characteristics of the recipients of the programme.
- 2) To investigate the impact on the volunteers' wellbeing of taking part in the peer support programme.

## **Methods**

### *Participants and Setting*

Volunteer Carer Supporters (CSs) were recruited to Carer Supporter schemes, either by voluntary sector organisations or by NHS volunteering programmes in the English counties of Norfolk, Northamptonshire, Berkshire or in four London boroughs. The Carer Supporter schemes ran between October 2009 and March 2013 as part of a wider research trial of peer support for family carers of people with dementia (Charlesworth et al., 2011).

CSs were recruited through adverts, leaflets and posters placed in voluntary sector newsletters, websites, buildings and more widely around the relevant local communities. Inclusion criteria were: being over the age of 18; having experience as a family carer of a person with dementia, but no ongoing direct responsibilities; able to provide two character referees; having a Criminal Records Bureau (CRB) Enhanced Disclosure.

Potential CSs were required to attend an awareness and orientation programme consisting of six modules: experiences of dementia and caring; the role of the CS; listening and helping skills; working safely in other people's homes; dementia awareness; and resources available to carers. The role of the CSs was to provide a listening ear, moral support, signposting to local services and resources, and to encourage carers to look after their own well-being. CSs were not to give advice, provide respite, and/or carry out tasks that would otherwise be performed by a paid worker.

After CSs successfully completed their registration, screening and training requirements, they were matched by the Scheme Coordinator to a family carer participating in the research programme (Charlesworth et al., 2011). Family carers were recruited through memory clinics, outpatient clinics, community psychiatric nurses, admiral nurses, psychiatrists, general practitioners, carers' registers, local media, and online carer support forums and websites. Inclusion criteria were that participants were adult carers (18 years and over) for a relative with dementia (defined by DSM-IV criteria) living at home. The matching process took into account volunteers' socio-demographic background, caring experience, common interests, and availability.

The duration of the matches was up to 10 months: weekly face-to-face or telephone contact of one hour over a three month period, followed by fortnightly contact over the subsequent seven months.

Eighty seven screened and trained CSs were matched with 109 family carers. Twenty Carer Support volunteers provided support to two or more family carers, usually sequentially.

### *Ethical approval*

Ethical approval for the trial and evaluation of the impact of volunteering on volunteers was gained from the Outer North East London Research Ethics Committee (09/H0701/54). Informed consent was obtained at the point of baseline assessment from both CSs and family carers (FCs).

### *Data Collection*

Demographic information (age, gender, ethnicity, relationship to the person with dementia they care/ cared for, type of dementia) was collected through interview by either Carer Supporter Coordinators (for CSs) or researchers (for FCs).

Self-completion questionnaire packs were distributed to CSs by the Carer Supporter Coordinators at their final Orientation and Awareness session and before matching. CSs were asked to complete the packs and return them to the research team by post. Further questionnaire packs were given to CSs between three and five months and between ten and 12 months after baseline for return by post. The timing of distribution of the packs was anchored to the end of the weekly and then monthly phases of a parallel group intervention that was forming part of the wider research programme (Charlesworth *et al.* 2011). Packs were linked by an ID code. This method ensured that the Carer Support Coordinator was blind to CS responses, and responses were anonymous from the researchers' perspective.

### *Psychometric measures*

*Personal Growth Index* (PGI; Ryff & Keyes 1995): A three-item subjective rating of an individual's development, openness to new experiences, sense of potential and improvement in self over time. A higher total score (range: 3-18) indicates higher personal growth. The scale demonstrates medium strength positive correlations with measures of happiness and life satisfaction and medium strength negative correlations with measures of depression and negative affect (Ryff & Keyes 1995).

*Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith 1983): a 14-item self-assessment scale of psychological morbidity with seven items evaluating anxiety and seven assessing depression. Each subscale has a range of 0-21 with a higher score indicating higher levels of depression or anxiety. The HADS has been used previously in studies involving carers of people with dementia (Charlesworth *et al.* 2008, Livingston *et al.* 2013) and has been shown to be good case finders for anxiety and depression and to have strong concurrent validity across a wide range of contexts and populations (Bjelland *et al.* 2002).

*Short Form-12 Health Survey* (SF-12; Ware *et al.* 1996): a 12-item measure of general health with two subscales, the Physical Component Summary (PCS) and the Mental Component Summary (MCS). A higher score is indicative of better mental and physical health. Reliability is 0.74 for the MCS and 0.78 for the PCS (Ware *et al.* 2009). Validity is 0.97 for MCS and 0.67 for PCS (Ware *et al.* 1996).

*Generalised Self-Efficacy Scale* (GSES; Schwarzer & Jerusalem 1995): a 10-item self-complete measure assessing an individual's general beliefs regarding their ability to respond to and control environmental demands and challenges. Higher scores reflect higher self-efficacy. The measure demonstrates good internal consistency (Cronbach's  $\alpha$  0.75-0.91) and test-retest reliability ( $r=.47 - .73$ ) (Scholz *et al.* 2002).

*Control, Autonomy, Self-Realisation, Pleasure* (CASP – 19; Hyde *et al.* 2003): a 19-item quality of life measure assessing each of these four domains with higher scores indicating higher levels of each domain. The domains have good internal consistency (Cronbach's  $\alpha = 0.59 - 0.77$ ) and the CASP demonstrates good concurrent validity ( $r=0.63$ ) with other measures of wellbeing.

As well as the psychometric questionnaires, CSs were asked to rate their current global health state on a visual analogue scale ranging from 0 (worst possible health state) to 100 points (best possible health state) (EQ-VAS; EuroQol Group 1990). The scale is significantly correlated with the EQ-5D Index (Whynes & TOMBOLA Group 2008) and therefore provides an overview of a standardised measure of health related quality of life (EuroQol Group 1990). There were also items on health services used in the past three months (type of service, number of appointments and average duration of appointment) and the numbers of hours per week volunteered (other than as a CS).

CSs also completed the Practitioner Assessment of Network Type (PANT; Wenger 1994). This is an eight item assessment of the presence and availability of local close family, frequency of interaction within networks and the degree of involvement

within the community. Individuals' responses are categorised into a social network typology: 'Family Dependent' (a highly dependent group of individuals whose network consists mainly of close family ties, with few friends and contact with neighbours); 'Locally Integrated' (a robust group of individuals in a long established network of family, friends and neighbours); and 'Local Self-Contained' (individuals relying mainly on neighbours with occasional family contact); 'Wider Community Focussed' (individuals with a large, mainly friendship focussed, network and high community involvement); 'Private Restricted' (the most isolated individuals with very small networks and no community involvement); and 'inconclusive' (when a type cannot be calculated).

Data from participating family carers was collected at baseline, five and 10 months as part of the wider research programme (Charlesworth *et al.* 2011).

### *Data Analysis*

All analysis was conducted using IBM SPSS 21 with an alpha level of 0.05.

For both baseline comparison of responders and non-responders, and comparison of CS volunteers and recipient family carers, difference in age was analysed using an independent t-test. In addition, 2x2 Chi Square analysis was used for dichotomized demographics, namely: kinship as 'vertical relationships' reflecting structural generational difference (i.e. caring for a parent, grandparent, aunt or uncle) and 'horizontal relationships' (i.e. caring for husband or wife or friend or sibling); Ethnicity as 'white British' and 'other'; and Dementia type as 'Alzheimer's disease' and 'other'. Social network types were analysed using 2 x 6 Chi Square.

All other measures were tested for normal distribution using the Kolmogorov-Smirnov test and visual analysis of histograms and P-P plots. Cross-sectional analysis of normally and non-normally distributed data were carried out using independent t-tests and the Mann-Whitney U-test respectively. Due to the low response rates at the two follow-up points, the follow-up data were collapsed to a single dataset using the last available follow-up for each volunteer. Longitudinal data demonstrating normal distribution were analysed using related samples t-tests and those showing non-normal distribution were analysed using the Wilcoxon matched-pair signed-rank test.

#### *Missing Data*

The percentage of CSs with missing data at baseline was below 5% on all measures with the exception of: age (five, 5.7%); type of dementia (10, 11.4%); number of health service contacts (six, 13%) and average duration of health service contacts (six, 13%). Longitudinal data for CSs contained missing data at follow up within the SF-12 (four, 19%) and the average duration of contact with services (two, 11%). For family carers, the percentage of participants with missing data at baseline was again below 5% on all measures with the exception of: type of dementia (10, 9.2%); EQ-VAS (three, 7%).

Missing data was dealt with through pairwise deletion: cases were only excluded from analyses involving the variable they were missing. Separate sensitivity analyses were run using imputed data where missing totals replaced by the mean total of the participant's group.

Where percentages are reported in the analysis they are percentages of the whole sample including cases with missing items.

## **Results**

### *Demographic characteristics*

Characteristics of the carer support volunteers and family carers are presented in Table 1. Of the 87 CSs, the majority were female (89%), and white British (90%) with similar numbers having cared for an older relative or spouse (53 vs 47%). Family carers were significantly older than Carer Supporters (68 years: 61 years), although the range of ages were similar (FCs 40-89 years: CSs 33-88 years). Kin relationships to the person with dementia differed with CSs significantly more likely to have cared for a parent, parent-in-law or grandparent (a ‘vertical’ relationship on a family tree) rather than a spouse or sibling (‘horizontal’ relationship) ( $z=2.2$ ,  $p<0.05$ ). CSs were marginally more likely to have cared for a person with Alzheimer’s disease ( $z= 1.2$ ,  $p> 0.05$ ). There was a significant association between gender and role with CSs being significantly less likely to be male ( $z = -2.6$ ,  $p< 0.01$ ).

.....

**Insert Table 1 near here.**

.....

.....

**Insert Table 2 near here.**

.....

Of the 87 CSs included in the study, 43 completed measures of network type (Table 1) and wellbeing (Table 2) at baseline (response rate 49%) and these are compared with the same measures completed by the 43 FCs with whom they were matched (first match only for CSs who were matched more than once). There were no significant differences in demographics between these dyads and the dyads who did not return baseline questionnaire measures.

Network type, as classified by the PANT, demonstrated no significant association with role in the study, with ‘Locally Integrated’ being the most commonly reported network type by both FCs and CSs.

CSs reported significantly higher personal growth (PGI) and self-rated global health (EQ-VAS) and significantly lower HADS-depression scores than FCs. However, there was no significant difference between the groups in terms of HADS-anxiety scores. Mean HADS scores for CSs and FCs were below the clinical cut-off for depression and anxiety (<8). However, the prevalence of cases differed between groups with 21% of CSs and 42% of FCs scoring above the cut-off for anxiety and 2% of CSs and 28% of FCs scoring above the cut-off for depression.

49% (21) of CSs reported having volunteered elsewhere in the last three months with a mean of four ( $SD = 3$ ) hours a week. 65% (28) of CSs reported using at least one health service in the past 3 months compared to 41% (18) of FCs, although the difference between the total number of health service contacts for the two groups was not significant. CSs also used significantly more unique services than FCs did. Participants reported using 18 different services, with GPs being the single most used service with 44% (19) of CSs and 23% (10) of carers visiting the GP at least once. Other services they used by CSs were diverse outpatient services whereas other services used by FCs were caring-related support services (e.g. carer support groups and Admiral Nurses). These caring-related support services were used for 111.67 minutes ( $SD = 37.58$ ), much longer than were CS outpatient services ( $M = 35.7$ ,  $SD = 45.8$ ). Difference in duration of GP contacts only was also analysed and found not to be significant.

#### *Comparison of CS wellbeing at baseline and follow up*

Of the 43 CSs who returned baseline measures, 21 (49%) also completed follow-up at either 3-5 months post-baseline ( $N=8$ ) or 10 months post-baseline ( $N=13$ ). Follow-up data therefore represents only 24% of the total sample of 87 volunteers. With the exception of those completing follow ups reporting higher levels of autonomy on the CASP-19 ( $U=254$ ,  $z=-2.39$ ,  $p=.017$ ) there were no significant differences in either demographics or baseline wellbeing measures between these CSs and those who returned baseline but not follow up data.

.....

**Insert Table 3 near here**

.....

Table 3 presents the comparison of baseline and longitudinal data for the well-being measures administered. There were significant reductions in personal growth (PGI) and in autonomy (CASP-autonomy) as well as an increase in mental wellbeing (SF12 MCS).

There was a slight increase in the number of CSs reporting having volunteered in the previous three months between baseline (33%, 7) and follow up (38%, 8) but there was no significant difference in time spent volunteering. The percentage of CSs using at least one health services was identical at both time points (57%) and there was no significant difference in the number of services used or for number or duration of contacts. GP services were the most used representing 25% of service use at baseline and 52% at follow up with an associated decrease in the number of other categories of services used, from 8 to 2.

*Correlations between CS change scores and duration of involvement.*

.....

**Insert Table 4 near here**

.....

Due to the varying lengths of provision of support by the volunteer CSs ( $M = 6.97$  months, range = 2-10), correlational analyses were conducted between duration of

involvement and CSs change scores on wellbeing measures (Table 4). Only the EQ-VAS showed a significant correlation with duration of involvement ( $r(19) = .44, p = 0.045$ ), indicating that self-rated global health increased more for CSs who volunteered for longer.

Repeating all the analyses above with imputed data produced results which followed the same trends of significance and non-significance.

## **Discussion**

This research provides a description of the demographic characteristics and wellbeing of peer support volunteers compared to those who they are supporting. It also examines the impact upon the volunteers of participating in the programme. The study was exploratory in nature as previous research has found evidence for both positive and negative impacts of volunteering. The main findings are that experienced carers of people with dementia who volunteer to support other carers are psychologically very well and remain so throughout volunteering. Volunteers are in better psychological health than those that they are supporting, with those that provide support for longer durations showing greatest improvements in self-rated health.

### *Volunteer Characteristics*

As anticipated, volunteers were more likely to be female. This replicates previous findings (Wilson 2000, Thoits & Hewitt 2001, Low *et al.* 2007) possibly because women are more likely to see volunteering as an extension of their unpaid caring roles

as wives and mothers (Wilson 2000) or the likelihood of comparable paid employment. The volunteers' average age and the kin-relationship to their previously supported relative (parent/older relative rather than spouse) also reflected previously reported characteristics of peer support volunteers (Sabir *et al.* 2003; Stewart *et al.* 2006). Spousal caregiving is a predictor of complicated grief which involves avoidance behaviours towards reminders of the person they cared for, and this may make it less likely that spouses would take part in such volunteering (Chan *et al.* 2013).

The volunteers' network types revealed high levels of community involvement, with an emphasis on established wider support from friends and neighbours. Prior community involvement was correspondingly high amongst the volunteers with half not only reporting volunteering in the last three months but having volunteered for almost a third more hours than the UK average (Time Bank 2014). In a qualitative study Larkin (2009) found that local community integration and volunteering formed an important part of 'constructing life post-caring' for former carers of older adults which might explain these findings.

### *Volunteer Wellbeing*

The volunteers were psychologically very well, scoring below the HADS clinical cut-off for anxiety and depression, with high levels of personal growth (PGI) and self-rated global health (EQ-VAS). This matches the higher levels of volunteer wellbeing reported by Sabir *et al.* (2003) and may be the result of disengagement from the psychological morbidities of a former role of carer and (re)integration with friends and the wider community. The results do not support the findings of Robinson-

Whelen *et al.* (2001) that higher levels of depression persist for years beyond the end of caring but this may reflect the self-selection aspect of volunteering for those who are psychologically resilient, or have responded to the challenges of caring with personal growth.

Volunteers were more likely to use at least one health service and to use more unique health services than the carers which may at first seem to contradict their self-reported high levels of wellbeing. However, it may be that such higher service use represents better self-care rather than worse health and this may be supported by the volunteers reporting high levels of self-efficacy, higher than that found in the general volunteering population (Brown *et al.* 2012). Higher self-efficacy is also associated with lower psychological morbidity (Gillian & Steffen 2006) and higher health-related quality of life in family carers of people with dementia (Crellin *et al.* 2014) and may represent the underlying mechanism for enabling the volunteers' wellness. Another possibility is that ex-carers simply have more free time and that part of 'constructing life post caring' is utilising this time to maintain good physical and mental health (Larkin 2009).

#### *Impact of Volunteering on the Volunteer*

Volunteers maintained their high levels of wellbeing throughout the programme, and indeed showed a small but significant increase in mental wellbeing (SF-12 MCS). That there might be a positive effect for the volunteers from participating in the programme is supported by the significant positive correlation found between duration of involvement in the programme and perceived wellbeing. In contrast, there were small but significant reductions in personal growth (PGI) and autonomy

(CASP). However, the reductions found in the measures may simply represent a longitudinal regression to the mean, as the baseline scores for both personal growth and autonomy are very high (above 88% of maximum score).

The quantitative findings from this study can be compared with qualitative insights from a recently published narrative enquiry into the volunteer peer supporters' experiences (Brooks *et al.* 2014). The participating CSs described both positive gains that are reflected in the general volunteering literature such as confidence, a sense of pride, enhanced self-esteem, and social connections. However, at times, negative emotions relating to the carers' own experiences were also evoked in the same volunteers. An important issue for the volunteers was a sense of connectedness with the person they were supporting, and a sense of 'getting something back' from the relationship (Brooks *et al.* 2014). This might be easier when volunteers are matched with carers who are also psychologically well, and the psychological health of the supported carer might influence volunteer wellbeing over time.

### *Limitations*

The response rates for the comparative analysis of wellbeing at baseline and the longitudinal analysis were both low, which has implications for the generalizability of results. The low response rate can be explained in part by the mechanism for data collection. Carer Supporters were not in direct contact with the research team and the questionnaire packs were distributed on behalf of the researchers by the Carer Supporter Coordinators embedded within the NHS or voluntary sector organisations. The 'impact of volunteering on the volunteer' project was secondary to a randomised controlled trial of peer support for which both volunteer CSs and the paid Carer

Supporter Coordinators were ‘contracted’ to provide data on time, expenses and session content. Therefore the completion of questionnaire packs for the ‘impact of volunteering’ study was considered a lower priority and there were times when Carer Supporter Coordinators either did not distribute questionnaire packs due to burden of other responsibilities, or did not feel it appropriate to make further requests of the CSs.

Although there were no demographic differences between those who did and did not return questionnaires, it may be that those who did not complete the follow-up questionnaires had different psychological profiles to those who did. Psychological characteristics and attitudes are known to be associated with wellbeing in volunteers. For example, Kahana and colleagues (2013) found that altruistic attitudes made a unique contribution to explaining variance in wellbeing when volunteering and informal helping behaviours had been taken into account in a large panel study of successful ageing.

The volunteers and family carers who participated in the research had ‘self-selected’, which also limits generalisability, particularly as previous findings have shown that older adults who volunteer (Morrow-Howell 2010) or participate in research (Dura & Kiecolt-Glaser 1990) are likely to be more psychologically well than those who do not. However, it could be argued that self-selection represents an integral feature of volunteering rather than a limitation of this study.

No analysis was conducted to examine how closely volunteers and family carers were matched on the matching criteria (socio-demographic background, caring experience

and common interests) and whether this correlated with the outcome measures. It might therefore be that the positive effect of the study upon volunteers was due to very close matching on these criteria rather than the participants simply being caregiving peers. However, previous research has found that matching criteria beyond both participants having an experience of dementia caregiving has no effect on the success of the match for either family carers or carer supporters (Sabir *et al.* 2003).

A final limitation is the extent to which the family carers in the study are representative of the wider population of carers of people with dementia. Similar to the volunteer CSs, although to a lesser extent, the family carers in the study also scored below the clinical cut-off for anxiety and depression as measured by the HADS. There is a longstanding view that caring is a stressful and burdensome role, with many studies attesting to caregiver depression, especially for family carers of people with dementia. However, a recent re-appraisal of the role indicates that psychologically healthy carers might be more representative than previously thought (Roth *et al.* 2015). The HADS scores for the family carers were not dissimilar to those for recent treatment trials of psychological interventions for family carers, for example Livingston and colleagues' START trial (Livingston *et al.* 2013).

### *Implications*

Future peer support services can proceed more confidently in recruitment of volunteers, acknowledging that the self-selection aspect of volunteering will lead to those at little risk from participation, and who indeed might benefit from it. However, 'readiness' to provide support remains an ethical consideration and future services

might consider assessing self-efficacy as an indication of volunteers' ability to provide support without self-detriment.

### *Future Research*

Future research should focus in redressing the limitations of the small sample and limited research duration to generate data which can be more representative of the volunteering population whilst investigating the impact of volunteering over a longer period of time and the impact of experiential similarity. Research which includes a comparison group of carers not volunteering for the programme would allow the issues raised above, such as the interaction between personal growth, autonomy and wellbeing, to be more systematically investigated and clarified. A large-scale study of volunteering by older people is currently underway in Australia (Pettigrew *et al.* 2015). A randomised controlled trial approach is being used with the aim of generating new knowledge relating to the physical and psychological health benefits of different levels and types of volunteering for older people. In addition to such endeavours, further qualitative studies are still required, for example to provide greater insight into the mechanisms through which experienced carers choose, or do not choose, to become volunteers.

### *Conclusion*

As the number of people with dementia increases, so too will the number of experienced carers willing to volunteer to support others. This study illustrates that those who self-identify as potential peer-support volunteers are a psychologically well population who can offer emotional support to others over time without detriment to their own health or well-being.

## References

Alzheimer's Society (2014) *Dementia 2014: Opportunity for change*. Alzheimer's Society, London, UK.

Aneshensel C.S., Pearlin L.I., Mullan J.T., Zarit S.H. & Whitlatch C.J. (1995) *Profiles in caregiving: the unexpected career*. Academic Press, San Diego, CA, USA.

Bakker A.B., Van Der Zee K.I., Lewig K.A. & Dollard M.F. (2007) The relationship between the big five personality factors and burnout: a study among volunteer counselors. *The Journal of Social Psychology* **146** (1), 31-50.

Beeson R., Horton-Deutsch S., Farran C. & Neundorfer M. (2000) Loneliness and depression in caregivers of persons with Alzheimer's disease or related disorders. *Issues in Mental Health Nursing* **21** (8), 779-806.

Bjelland I., Dahl A.A., Haug T.T. & Neckelmann D. (2002) The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *Journal of Psychosomatic Research* **52** (2), 69-77.

Brooks A., Farquharson L., Burnell K. & Charlesworth G. (2014) A narrative enquiry of experienced family carers of people with dementia volunteering in a carer supporter programme. *Journal of Community & Applied Social Psychology [e-journal]* Available from: <http://onlinelibrary.wiley.com/doi/10.1002/casp.2188>

Brown K.M., Hoye R. & Nicholson M. (2012) Self-Esteem, self-efficacy, and social connectedness as mediators of the relationship between volunteering and well-Being. *Journal of Social Service Research* **38** (4), 468-483.

Burnell K., Hoe J., Miranda C., Aguirre E., Streater A., Charlesworth G. & Orrell M. (2009) Introducing “Support at Home: Interventions to Enhance Life in Dementia (SHIELD)”: Five Year Research Programme funded by the National Institute for Health Research. *Generations Review [e-journal]* **19** (2), Available from: <http://www.britishgerontology.org>

Cabinet Office (2013) *Giving of time and money: Findings from the 2012-13 community life survey*. TNS BMRB, London, UK.

Chan D., Livingston G., Jones L. & Sampson E.L. (2013) Grief reactions in dementia carers: a systematic review. *International Journal of Geriatric Psychiatry* **28** (1), 1-17.

Charlesworth G.M., Burnell K., Beecham J. *et al.* (2011) Peer support for family carers of people with dementia, alone or in combination with group reminiscence in a factorial design: study protocol for a randomised controlled trial. *Trials [e-journal]* **12**, 205. Available from: <http://www.ncbi.nlm.nih.gov/pmc/journals>

Charlesworth G.M., Shepstone L., Wilson E., Thalanany M., Mugford M. & Poland F. (2008) Does befriending by trained lay workers improve psychological well-

being and quality of life for carers of people with dementia, and at what cost? A randomised controlled trial. *Health Technology Assessment* **12** (4), 1-78.

Crellin N. E., Orrell M., McDermott O. & Charlesworth G. (2014) Self-efficacy and health-related quality of life in family carers of people with dementia: a systematic review. *Aging and Mental Health* **19**, 1-16.

Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy*. HMSO, London, UK.

Doran T., Drever F. & Whitehead M. (2003) Health of young and elderly informal carers: analysis of UK census data. *British Medical Journal* **327** (7428), 1388.

Dura J.R. & Kiecolt-Glaser (1990) Sample bias in caregiving research. *Journal of Gerontology: Psychological Sciences* **45** (5), 200-204.

EuroQoL Group (1990) EuroQoL: a new facility for the measurement of health related quality of life. *Health Policy* **16**, 199-208.

Gaugler J.E., Anderson K.A., Leach C.R., Smith C.D., Schmitt F.A. & Mendiondo M. (2004) The emotional ramifications of unmet need in dementia caregiving. *American Journal of Alzheimer's Disease and Other Dementias* **19** (6), 369-380.

Gilliam, C. & Steffen, A. M. (2006) The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. *Aging & Mental Health* **10** (2), 79-86.

Greenwood N. & Habibi R. (2014) Carer mentoring: A mixed methods investigation of a carer mentoring service. *International Journal of Nursing Studies* **51**, 359-369.

Grimm R., Spring K. & Dietz N. (2007) *The health benefits of volunteering: a review of recent research*. Corporation for National and Community Service, Office of Research and Policy Development, Washington DC, USA.

Hogan B.E., Linden W. & Najarian B. (2002) Social support interventions: do they work? *Clinical Psychology Review* **22**, 381-440.

Hyde M., Wiggins R.D., Higgs P. & Blane D.B. (2003) A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP-19). *Aging & Mental Health* **7** (3), 186 - 194.

Kahana, E., Bhatta, T., Lovegreen, L. D., Kahana, B., & Midlarsky, E. (2013). Altruism, helping, and volunteering pathways to well-being in late life. *Journal of Aging and Health*, 25(1), 159-187.

- Larkin, M. (2009). Life after caring: the post-caring experiences of former carers. *British Journal of Social Work*, 39(6), 1026-1042.
- Liang J., Krause N.M. & Bennett J.M. (2001) Social exchange and well-being: is giving better than receiving? *Psychology and Aging* **16** (3), 511-523.
- Livingston G., Barber J., Rapaport P. *et al.* (2013) Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial. *BMC* **347** (f6276), 1-14.
- Low N., Butt S., Paine A.E. & Smith J.D. (2007) *Helping out: a national survey of volunteering and charitable giving*. Cabinet Office, London, UK.
- Lum T.Y. & Lightfoot E. (2005) The effects of volunteering on the physical and mental health of older people. *Research on Aging* **27** (1), 31-55.
- Mahoney R., Regan C., Katona C., Paton J. & Lyketsos C. (2005) Anxiety and depression in family caregivers of people with Alzheimer's disease. *American Journal of Psychiatry* **162** (11), 1996-2021.
- Morrow-Howell, N. (2010). Volunteering in later life: research frontiers. *Journal of Gerontology: Social Sciences* **65B** (4), 461-469.

Narushima M. (2005) 'Payback time:' community volunteering among older adults as a transformative mechanism. *Ageing and Society* **25**, 567-584.

Nazroo, J & Matthews, K. (2012). *The impact of volunteering on well-being in later life*. Royal Voluntary Service, Cardiff, UK. Available at:

[http://www.royalvoluntaryservice.org.uk/Uploads/Documents/Reports%20and%20Reviews/the\\_impact\\_of\\_volunteering\\_on\\_wellbeing\\_in\\_later\\_life.pdf](http://www.royalvoluntaryservice.org.uk/Uploads/Documents/Reports%20and%20Reviews/the_impact_of_volunteering_on_wellbeing_in_later_life.pdf)

Nolan M. (2001) Working with family carers: towards a partnership approach. *Reviews in Clinical Gerontology* **11**, 91-97.

Office for National Statistics (2002) *Carers 2000. General Household Survey*.

Her Majesty's Stationery Office, London, UK.

Ory M.G., Hoffman R.R., Yee J.L., Tennstedt S. & Schulz, R. (1999) Prevalence and impact of caregiving: a detailed comparison between dementia and non-dementia caregivers. *Gerontologist* **39**, 177-185.

Pettigrew, S., Jongenelis, M., Newton, R. U., Warburton, J., & Jackson, B. (2015).

Research protocol for a randomized controlled trial of the health effects of volunteering for seniors. *Health and quality of life outcomes*, *13*(1), 74.

Pillemer K. & Suitor J. (2002) Peer support for Alzheimer's caregivers: is it enough to make a difference? *Research in Aging* **24**, 171-192.

Pinquart M. & Sörensen S. (2003) Differences between caregivers and non-caregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging* **18**, 250-267.

Robinson-Whelen S., Tada Y., MacCallum R.C., McGuire L. & Kiecolt-Glaser J.K. (2001) Long-term caregiving: what happens when it ends? *Journal of Abnormal Psychology* **110** (4), 573-584.

Rook K.S. & Sorkin D.H. (2003) Fostering social ties through a volunteering role: Implications for older adults' psychological health. *International Journal of Aging and Human Development* **57** (4), 313-337.

Ross M.W., Greenfield S.A. & Bennett L. (1999) Predictors of dropout and burnout in AIDS volunteers: a longitudinal study. *AIDS Care* **11** (6), 723-731.

Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, gnu177.

Ryff C.D. & Keyes C.L.M. (1995) The structure of psychological well-being revisited. *Journal of Personality & Social Psychology* **69**, 719-727.

Sabir M., Pillemer K., Sutor J. & Patterson M. (2003) Predictors of successful relationships in a peer support programme for Alzheimer's caregivers.

*American Journal of Alzheimer's Disease and Other Dementias* **18** (2), 115-122.

Scholz U., Doña B.G., Sud S. & Schwarzer R. (2002) Is general self-efficacy a universal construct? Psychometric findings from 25 countries. *European Journal of Psychological Assessment* **18** (3), 242-251.

Schwarzer R. & Jerusalem M. (1995) Generalised Self-Efficacy Scale. In: J. Weinman, S. Wright & M. Johnson (Eds) *Measures in health psychology: A user's portfolio*. NFER-NELSON, Windsor, UK.

Smith R. & Greenwood N. (2014) The impact of volunteer mentoring schemes on carers of people with dementia and volunteer mentors: a systematic review. *American Journal of Alzheimer's Disease & Other Dementias* **29** (1), 8-17.

Stewart M., Barnfather A., Neufeld A., Warren S., Letourneau N. & Liu, L. (2006) Accessible support for family caregivers of seniors with chronic conditions: from isolation to inclusion. *Canadian Journal on Aging / La Revue canadienne du vieillissement* **25**, 179-192. doi:10.1353/cja.2006.0041.

Thoits P.A. & Hewitt L.N. (2001) Volunteer work and well-being. *Journal of Health and Social Behavior* **42** (2), 115-131.

Time Bank (2014) *Key Facts*. [online] Available at: <http://timebank.org.uk/key-facts>. [Accessed 05/08/2014].

- Van Willigen M. (2000) Differential benefits of volunteering across the life course. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* **55**, S308-S318.
- Ware J., Kosinski M. & Keller SD (1996) A 12-Item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity. *Med Care* **34**, 220-233.
- Ware J., Kosinski M., Turner-Bowker D.M. & Gandek B (2009) *User's manual for the SF-12v2 health survey: with a Supplement documenting the SF-12® health survey*. QualityMetric Incorporated, Massachusetts, USA.
- Wenger G.C. (1994) *Support networks of older people: a guide for practitioners*. Centre for Social Policy Research and Development, Bangor, UK.
- Whynes D.K. & TOMBOLA Group (2008) Correspondence between EQ-5D health state classifications and EQ VAS scores. *Health and Quality of Life Outcomes* **7** (6), 94.
- Wilson J. (2000) Volunteering. *Annual Review of Sociology* **26**, 215-240.
- Yeandle S., Bennett C., Buckner L., Fry G. & Price C. (2007) *Stages and transitions in caring*. Her Majesty's Stationery Office, University of Leeds, UK.

Table 1

Zigmond A.S. & Snaith R.P. (1983) The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica* **67**, 361-370.

Table 2  
 CS and FC demographics and network type comparison  
 Comparison of CS and FC wellbeing at baseline

	CSs		FCs		Comparison		p
	Mean	SD	Mean	SD	U	Z	
Age, mean (SD)	60.98	11.88	67.78	10.98	179	-4.091	< 0.001
PGI	15.9	2	11.9	2.5	518	-6.43	< 0.001
EQ-VAS	81	13.9	69.4	19.3	1094	-2.87	0.004
HADSa	5.24	3.3	6.65	3.6	1319.5	1.91	0.056
Gender							
Male	2.78	2.89	5.79	3.71		3.95	< 0.001
Female	10	11.5	40	36.7			
Network							
Monique	1.17	12.5	0.69	0.93	682	16.22	< 0.001
Ethnicity							
White British	78	89.7	97	89			
Other	9	10.3	12	11		$\chi^2 (1) = 0.02$	0.881
Relationship with PwD							
Vertical	44	53	29	26.6			
Horizontal	39	47	80	73.4		$\chi^2 (1) = 13.94$	< 0.001
Dementia type							
Alzheimer's	54	70.1	51	46.8			
Other	23	29.9	48	44		$\chi^2 (1) = 6.24$	0.013
Network type(PANT)							
Family dependent	4	9.3	9	20.9			
Locally integrated	17	39.5	16	37.2			
Local self-contained	10	23.3	8	18.6			
Wider community focussed	5	11.6	6	14			
Private restricted	3	7	1	2.3			

Table 3

*Comparison of CS wellbeing at baseline and final follow up*

services used	Baseline		Follow up		Wilcoxon matched-pair signed-rank		
	Mean	SD	Mean	SD	W	Z	p
No. of contacts	7.56	3.3	17.7	3.25	721.5	-1.87	0.061
PGI	16.29	1.82	14.67	2.54	8	-2.81	0.005
Mean duration of HADSa contact (mins)	25.97	37.48	50.26	50.44	764	1.85	0.064
HADSd	5.00	2.92	5.33	3.10	98.5	0.14	0.886
Mean duration of CASPa GP contact (mins)	2.81	3.28	2.43	2.77	45	-1.22	0.224
CASPb	10.21	4.97	11.11	11.76	92	0.93	0.356
CASPP	12.33	2.11	11.43	1.94	86.5	-2.16	0.031
	10.14	1.62	7.33	2.67	15	-1.92	0.055

SF12MCS	33.88	3.10	35.83	3.97	84	1.98	0.048
SF12PCS	26.14	5.39	29.11	5.70	80	1.73	0.084
Hours Volunteering	1.45	3.02	2.45	4.9	10	0.67	0.5
No. of unique services used	.86	1.06	.71	.72	31	-.66	.59
No. of contacts	1.48	2.04	1.33	1.85	52	-.46	.645
Duration (mins)	21.25	23.32	11.25	3.11	30.5	-1.39	.166

---

Related samples t-test

---

					<u>t</u>	<u>df</u>	<u>p</u>
GSE	33.14	3.40	32.62	4.06	0.93	20	0.363
EQ-VAS	80.74	12.62	80.52	14.08	0.1	20	0.924
CASPC	13.33	3.10	12.95	3.37	0.56	20	0.584
CASPSr	8.24	2.77	7.33	2.67	1.32	20	0.202

---

Table 4.

*Change score correlations*

	Duration	PGI	GSE	EQ-VAS	HADSa	HADSd	CASPC	CASPa	CASPp	CASPsr	SF-12 MCS	SF-12 PCS
Duration	1.00	-.14	.37	.44*	.02	-.19	.11	.19	.14	-.26	-0.12	0.08

\*. Correlation is significant at the 0.05 level (2-tailed).