

Accepted Manuscript

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PII: S0167-4943(18)30041-4
DOI: <https://doi.org/10.1016/j.archger.2018.03.005>
Reference: AGG 3642

To appear in: *Archives of Gerontology and Geriatrics*

Received date: 19-6-2017
Revised date: 25-10-2017
Accepted date: 2-3-2018

Please cite this article as: Smith, Raymond, Drennan, Vari, Mackenzie, Ann, Greenwood, Nan, The impact of befriending and peer support on family carers of people living with dementia: A mixed methods study. *Archives of Gerontology and Geriatrics* <https://doi.org/10.1016/j.archger.2018.03.005>

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The impact of befriending and peer support on family carers of people living with dementia: A mixed methods study

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Highlights

- Whilst little measurable impact on emotional health and loneliness from the outcome scales was found, carers described talking to the volunteers and sharing their feelings as valuable. This led them to feel emotionally supported, enabled them to cope with difficult situations and to continue caring.
- Quantitative results showed statistically significant improvements in perceived social support from a significant other. This was corroborated by the qualitative findings, with carers reporting they were no longer socially isolated and felt supported by the volunteers.
- The development of successful befriending and peer support relationships was often facilitated by the similarity of the carers' and volunteers' characteristics and the shared experience of caring.

Abstract

Background: Volunteer led befriending and peer support is provided to a wide range of people with varying needs. Despite large numbers such schemes for carers of people with dementia, there is little evidence for any benefits they may offer. The aim of this research was to investigate the impact of befriending and peer support on carers of people with dementia and to explore their experiences of receiving the interventions using a mixed methods approach.

Methods: Nineteen carers of people with dementia were recruited from befriending and peer support services. Carers completed the Hospital Anxiety and Depression Scale (HADS), the Multidimensional Scale of Perceived Social Support (MSPSS) and UCLA Loneliness Scale at baseline, three months and six months. Of the 16 carers who completed the quantitative phase, eight took part in in-depth semi-structured interviews.

Results: A statistically significant increase in perceived social support from a significant other between baseline and three months was found ($Z = 2.487$, $p = 0.013$). Qualitative findings showed befriending and peer support to be important sources of emotional and social support for carers, which was facilitated by the volunteers' experiential similarity.

Conclusion: Volunteer led befriending and peer support offers carers of people with dementia emotional and social support which enables them to cope better with challenges and continue caring. This has important implications for potentially reducing breakdowns in carer mental and physical health. Future research should explore whether these findings are replicable in other locations and in more diverse populations.

Key words: carers; caregivers; befriending; peer support; volunteers; dementia

Background

As of 2015, approximately 46.8 million people were living with dementia worldwide, with 131.5 million people expected to be living with the condition by 2050 (Prince et al. 2015). Europe and North America accounted for just under one third of the 2015 total with 15.3 million diagnoses (Prince et al. 2015). As the number of people living with dementia rises, so too does the number of carers (also known as family or informal carers) who play the major role in supporting them. For example, in the United Kingdom (UK) the number of carers of people with dementia is expected to increase from just over 700,000 in 2014, to approximately 1.7 million by 2050 (Lewis et al. 2014).

Satisfaction and enjoyment associated with caring are increasingly being reported (Mackenzie & Greenwood, 2012), however caring is also linked with well documented negative consequences on physical and mental health (Newbronner et al. 2013). Carers of people with dementia are known to be under more mental and physical strain than carers of people with other long-term conditions and non-carers (Brodaty et al. 2014; Pinquart & Sörensen, 2007; Svendsboe et al. 2016).

In response to these reported challenges, many countries have developed policies which directly or indirectly target carers of people with dementia. For example, in England there are national strategies to support carers, in particular through the development of social support services (Department of Health [DH], 2008; DH, 2009). More recently, other European countries (e.g. Ireland, France, Italy, Denmark, and the Netherlands) have published National Dementia Strategies, with the aim of developing services to support

people with dementia and their carers (Alzheimer Europe, 2015). Although slow progress is being made in updating strategies for carers and people with dementia, their development highlights the increasing international awareness of the need to develop infrastructure to support those (and those who care for them) at the end of life.

Psychological and social support interventions which aim to support carers in the community include: Admiral Nurses (specialist dementia nurses); counselling; psychoeducational training (Bunn et al. 2016; Dickinson et al. 2017). There are also group social support interventions carers and people with dementia can attend together, such as: dementia cafés (Greenwood et al. 2017); reminiscence and 'singing for the brain' groups (Osman et al. 2016; Woods et al. 2012). Although some of these interventions have been found to have little positive impact on coping ability and carer health (Thompson et al. 2007), there is evidence to suggest some offer better outcomes than others. For example, educational interventions have been shown to reduce caring related stress or 'overload' (Devor & Renvall, 2008). Increasingly, there has been an emphasis on supporting carers in the community with volunteer led befriending or peer support interventions (DH, 2008; DH, 2009).

Befriending and peer support

Befriending and peer support have been shown to offer benefits to a range of populations with varying needs, for example reducing depression (Mead et al. 2010), improving coping ability (Bjorck & Klewicki, 1997) and reducing social isolation and loneliness (Dean & Goodlad, 1998; Mulvihill, 2011). However, their use with and impact on carers of people with dementia is unclear (Smith & Greenwood, 2014a), with some quantitative research showing little measurable positive impact on mental health and quality of life outcomes (Charlesworth et al. 2008; Charlesworth et al. 2016), whilst qualitative research has shown carers value the opportunity to share difficult experiences and gain advice from volunteers (Greenwood et al. 2013).

Befriending and peer support are provided in a variety of ways (e.g. face to face, telephone, internet support and mixtures of these), they also generally have similar aims and goals of reducing emotional stress, loneliness and social isolation (Smith & Greenwood, 2014b).

However there are some distinctions, for example Dean and Goodlad (1998) defined befriending as:

“A relationship between two or more individuals which is initiated, supported and monitored by an agency that has defined one or more parties as likely to benefit. Ideally the relationship is non-judgemental, mutual, purposeful, and there is a commitment over time” (p. 5).

Whilst a peer supporter can be defined as:

“...someone who has faced the same significant challenges as the support recipient, (and) serves as a mentor to that individual” (Sherman et al. 2004, p. 140).

Even with these distinctions, there may be some similarities in the mechanisms by which these interventions have an impact. These have been explored previously, for example with volunteers having had similar past experiences as the carers, also known as experiential similarity, (Pillemer & Sutor, 2002) known to be important in facilitating positive benefits for carers (Greenwood & Habibi, 2014; Keyes et al. 2014; Veith et al. 2006). However, the degree to which this is important to carers of people with dementia is poorly understood.

The aim of this research was therefore to investigate the impact of befriending and peer support on carers of people with dementia and to explore their experiences surrounding receiving the support using mixed methods. This approach was chosen in order to build on previous quantitative findings (e.g. from the BECCA Trial: Charlesworth et al. 2008) which found little impact of befriending, and qualitative findings (Greenwood et al. 2013) which found that carers reported positive benefits, for example reduced social isolation, and also greatly valued peer support. This research formed part of a wider research project which also explored the experiences of the volunteers delivering the support (Smith et al. 2017).

The research questions were:

1. What impact does befriending and peer support have on carers of people with dementia?
2. How do carers experience receiving befriending or peer support?
3. What mechanisms are important in successful befriending and peer support relationships?

Methods

A sequential explanatory mixed methods design (Creswell & Plano Clark, 2011) was used and consisted of two interconnected phases. Priority was given to the initial quantitative phase, which involved the use of repeated measures and validated rating scales. A second qualitative phase was used to explore and explain the quantitative findings.

Quantitative phase

Participant recruitment

To take part, carers needed to be receiving one-to-one befriending or peer support from volunteers on at least a weekly basis. Carers were excluded if they paid to receive the service or were not caring for a person with dementia.

Convenience sampling (Patton, 2002) was used to recruit carers. Participants were recruited from volunteer befriending or peer support services ($n = 7$) in South East England. In order to comply with the Data Protection Act (1998), service managers assisted in recruitment of carers by sending information sheets and return forms to carers on the researchers' behalf. Carers then contacted the researcher directly if they wished to participate.

Informed consent was obtained from all participants before data collection. The purpose of the research, confirmation that their participation is voluntary and the participants' right to withdraw at any time were repeated verbally. They were informed that they were under no obligation to answer any of the questions and did not have to give a reason for not doing so.

Data collection

Quantitative data were collected through structured survey interviews at baseline, three months and six months. Carer participants could either receive the questionnaires by post or a researcher would visit them at home. Carers were contacted again at three months and six months to confirm whether they still wanted to take part and were still receiving the intervention.

Outcome measures

Participants were asked to complete a questionnaire collecting demographic details such as age, gender, ethnicity, nationality and marital status. Validated rating scale questionnaires measured depression and anxiety (the Hospital Anxiety and Depression Scale [HADS]);

Zigmond & Snaith, 1983); loneliness (the University of California, Los Angeles [UCLA] Loneliness Scale (version 3), (Russell, 1996) and perceived social support (the Multidimensional Scale of Perceived Social Support [MSPSS]; Zimet et al. 1988).

Quantitative data analysis

As this research used a repeated measures design and the data were ordinal, the non-parametric Friedman test was used. Post-hoc analysis was conducted using the Wilcoxon Signed-Rank test. To avoid type I error, the Bonferroni adjustment was calculated as 0.017 by dividing the pre-defined alpha level ($p = 0.05$) and dividing it by the three post hoc tests ($0.05/3 = 0.017$):

1. Baseline and three month follow up
2. Baseline and six month follow up
3. Three month follow up and six month follow up

A p value of less than 0.017 resulting from the post hoc tests was considered significant. Data were analysed using the Statistical Package for the Social Sciences (SPSS version 17).

Qualitative phase

Qualitative data were collected from carers using semi-structured interviews. Interviews took place at carers' homes or over the telephone at a time convenient for them. The approach was exploratory and semi-structured interviews allowed for rich and in-depth data collection.

Participant recruitment

Carers were eligible to take part here if they completed the three month follow up questionnaires. The carers were contacted by telephone to determine whether they wished to take part in a single interview about their views and experiences of befriending and peer support.

Again, participants were informed prior to starting the interview that they could withdraw at any time without giving a reason and the information they already provided would be destroyed if they wished. Consent was gained before the interview was digitally recorded and carers informed that it would be transcribed with all identifying information removed. Recordings were permanently deleted upon transcription.

Interviews

Topic guides were used in order that important *a priori* areas derived from previous research findings (Greenwood et al. 2013; Greenwood & Habibi, 2014; Smith & Greenwood, 2014a; Smith & Greenwood, 2014b) were covered (Bowling, 2002). The only difference between the topic guides were the replacing of 'befriending' with 'peer support' depending on the intervention received. The topic guide focussed on the experiences and perceptions of how, if at all, befriending and peer support impacted on carers, and their perceptions of the importance of experiential similarity (former caring experience of the volunteer) and 'matching' (being paired with a volunteer based on similar characteristics, e.g. age, gender and hobbies).

Qualitative data analysis

Qualitative data gathered from the interviews were transcribed and analysed for themes using Framework Analysis (Richie & Spencer, 1994). Transcripts were read by one author (XX) to allow familiarisation with the data, followed by a second author (XX) who read a sample of transcripts. From this the framework was developed which was applied back to the transcripts to check how well it fitted the raw data. This led to a further refinement of the framework in which themes and subthemes were merged together and agreement was reached by both researchers regarding the emerging themes and subthemes.

The qualitative data analysis software package NVivo 10 (QSR International, 2012) was used to organise the data.

Ethics

The conduct of the research was informed by Economic and Social Research Council Framework for Research Ethics (ESRC, 2010). A favourable ethical review was gained from the XXXXXXXXXXXX Ethics Committee.

Results

Carer participant demographic characteristics

The age of carers who took part in the quantitative phase ranged from 34 to 85 years (mean 63.6), were largely female (73.7%) and almost all described their ethnicity or nationality as white British (94.7%). The majority of carers were spouses of the person with dementia (68.4%) and nearly half had been caring for less than three years (47.4%). A subsample of

eight carers took part in the qualitative phase (five were receiving peer support and three befriending). Their demographic details are available in Table 1.

Table 1. Carer participant demographic characteristics

| | Quantitative phase (n = 19) | Qualitative phase (n = 8) |
|---------------------------|--------------------------------|------------------------------|
| Mean age in years (range) | 63.6 (34-85) | 64.1 (41-85) |
| Gender | | |
| Female | 14 (73.7%) | 3 (37.5%) |
| Male | 5 (26.3%) | 5 (62.5%) |
| Marital status | | |
| Married | 16 (84.2%) | 7 (87.5%) |
| Single | 3 (15.8%) | 1 (12.5%) |
| Ethnicity and nationality | | |
| White British | 18 (94.7%) | 8 (100%) |
| Missing | 1 (5.3%) | 0 |
| Relationship to PWD | | |
| Spouse | 13 (68.4%) | 6 (75%) |
| Adult child | 5 (26.3%) | 2 (25%) |
| Adult grandchild | 1 (5.3%) | 0 |
| Length of time caring | | |
| < 3 years | 9 (47.4%) | 3 (37.5%) |
| 3 – 5 years | 7 (36.8%) | 4 (50%) |
| 6 – 8 years | 3 (15.8%) | 1 (12.5%) |
| Support type received | | |
| Befriending | 11 (58%) | 3 (37.5%) |
| Peer support | 8 (42%) | 5 (62.5%) |

*PWD – person with dementia

Quantitative findings

A total of 19 carers took part in the quantitative phase (11 received befriending and 8 peer support). Retention was 100% at three month follow-up and 84% at six month follow-up (three carers withdrew from the study). Details of withdrawal were: no longer wanting to take part (2) and no reason given (1).

No statistically significant reductions were found in reported depression, anxiety and loneliness between baseline, three and six month follow up (Table 2). However, there were non-statistically significant trends for reductions in reported depression ($\chi^2(2) = 0.448, p = 0.79$) and loneliness ($\chi^2(2) = 3.226, p = 0.19$) over the three time points (Table 2). There was a statistically significant difference in overall perceived social support between baseline, three months and six months ($\chi^2(2) = 6.317, p = 0.042$).

Post hoc analysis were carried out with Wilcoxon signed-rank tests with a Bonferroni correction, with a new significance level being set at 0.017 ($\alpha = 0.05/3 = 0.017$). Median (interquartile range) perceived social support scores for baseline, three months and six months were 53 (44 to 60), 60 (55 to 67) and 60.5 (49.25 to 64.75) respectively. Despite an increase in overall perceived social support, there were no statistically significant differences between baseline and six months ($Z = 1.683, p = 0.092$) or between three months and six months ($Z = -1.061, p = 0.289$). However, there was a weak but statistically significant increase in overall perceived social support between baseline and three months ($Z = 2.442, p = 0.015$).

The three subscales of the MSPSS (family, friends and significant others) were subjected to the Friedman test. There was a statistically significant difference in perceived social support from significant others between baseline, three months and six months follow up ($\chi^2 (2) = 11.179, p = 0.004$), (Table 2). Post hoc analyses were carried out with Wilcoxon signed-rank tests with a Bonferroni correction, with a new significance level set at 0.017 ($\alpha = 0.05/3 = 0.017$). No statistically significant difference was found between baseline and six months follow up ($Z = 1.582, p = 0.114$) or between three months and six months follow up ($Z = 1.937, p = 0.053$). However, there was a statistically significant increase in perceived social support from significant others between baseline and three months follow up ($Z = 2.487, p = 0.013$).

Table 2. HADS, UCLA and MSPSS scores at baseline, three months and six months

| *n = 16 | | Baseline | 3 months | 6 months | p value |
|------------------------|-----------|-----------------|-----------------|-----------------|----------------|
| <i>HADS anxiety</i> | | | | | |
| | Mean (SD) | 8.94 (4.15) | 8.69 (4.78) | 8.63 (4.31) | $p = 0.78$ |
| | Range | 4-16 | 2-17 | 3-15 | |
| <i>HADS depression</i> | | | | | |
| | Mean (SD) | 7.13 (4.04) | 6.81 (4.21) | 6.94 (4.41) | $p = 0.79$ |
| | Range | 2-13 | 1-16 | 1-15 | |
| <i>UCLA loneliness</i> | | | | | |
| | Mean (SD) | 49.13 (7.16) | 46.56 (9.98) | 46.13 (9.01) | $p = 0.19$ |
| | Range | 37-61 | 30-64 | 30-61 | |
| <i>MSPSS (overall)</i> | | | | | |
| | Mean (SD) | 52.69 (11.70) | 61.06 (10.27) | 58.38 (8.40) | $p = 0.042$ |
| | Range | 34-80 | 40-79 | 42-71 | |
| <i>MSPSS (family)</i> | | | | | |
| | Mean (SD) | 16.44 (7.06) | 18.13 (5.72) | 17.5 (5.65) | $p = 0.58$ |
| | Range | 4-28 | 4-25 | 4-25 | |

| | | | | | |
|-------------------------------------|-----------|--------------|--------------|--------------|-------------|
| MSPSS (<i>friends</i>) | | | | | |
| | Mean (SD) | 17.50 (4.67) | 20 (4.85) | 20.38 (4.67) | $p = 0.20$ |
| | Range | 11-28 | 11-28 | 12-28 | |
| MSPSS (<i>significant others</i>) | | | | | |
| | Mean (SD) | 19 (4.81) | 22.94 (4.43) | 21.19 (4.82) | $p = 0.004$ |
| | Range | 8-28 | 12-28 | 13-28 | |

HADS – Hospital Anxiety and Depression Scale; MSPSS – Multidimensional Scale of Perceived Social Support; UCLA - University of California, Los Angeles

*Three participants did not complete the six months follow up and were excluded from the analysis

Qualitative findings

Interviews lasted from between 20 and 45 minutes and all were audio recorded. Of the eight carers who were interviewed, six were conducted face-to-face and two over the telephone.

Themes

Three main themes were identified through the analysis: 1) the aspects of befriending and peer support that enable the development of successful relationships; 2) carers feel listened to; and 3) someone there just for the carer (Table 3). The themes with their subthemes are presented in Table 3. These themes are now presented in detail with exemplar quotations for which participants were assigned pseudonyms to provide anonymity.

Table 3. Themes and subthemes

| Themes | Subthemes |
|---|--|
| Aspects of befriending and peer support that enable the development of successful relationships | <ul style="list-style-type: none"> • Experiential similarity • Volunteer characteristics |
| Carers feel listened to | <ul style="list-style-type: none"> • Creating a safe environment • Sustaining emotions • Helping them get through difficult situations |
| Someone there just for the carer | <ul style="list-style-type: none"> • Advice and information • Personalised support • Carers look forward to the support • Reduced social isolation |

Aspects of befriending and peer support that enable the development of successful relationships

Within this overarching theme there were two sub themes: experiential similarity and volunteer characteristics.

Experiential similarity

The experiential similarity of some volunteers, in terms of former personal caring experience of a person with dementia, was one of the most important elements of befriending and peer support reported by carers. This was something they valued about the volunteers and was linked to a number of other themes and subthemes. For example, because of their own experiences, some volunteers were able to pass on advice and information about practical issues such as benefit entitlements and other support services. Discussing challenges was reported to be facilitated by the volunteers' prior caring experience, as it enabled the carers and volunteers to build stronger, trusting bonds. This was often reported as critical to the formation of a safe environment in which to share feelings, as one carer explained:

Sue. "I think because to understand what somebody's going through I think that person needs to experience...have had experience of something of that situation...and it gives them the ability to understand better how you're feeling and how to help you...because I don't think anyone understands better than someone who has been in the same situation, you know, on how to cope or give advice or even help".

It was commonly reported by carers, that if the volunteer understood the situation through the shared experience of caring, it helped them to express their emotions and talk about the difficulties they faced. One carer commented how it would be frustrating if the volunteer lacked prior caring experience:

Laura. "If someone has no idea about dementia or I think most have Alzheimer's then you know, I mean that could be a bit frustrating...I need to talk about all these things with someone who 'gets it'."

Volunteer characteristics

Some carers talked about how having a volunteer of a similar age and interests helped them to bond faster. Generally female carers reported having a female volunteer was important, with some specifically asking for a female befriender. Some of the male carers did not suggest the gender of the volunteer would be an issue, however having a similar personality and interests were important to them. When asked about the possibility of matching, a male carer replied:

David. *"...I like the idea of having somebody who's a similar age and a few similar interests so we can gel together a bit better so I always would think that's a good idea, yeah....I like the idea of that."*

Other volunteer characteristics viewed as important to carers were a cheerful and positive attitude, being sympathetic and empathetic, and a warm person who is patient and considerate. These were all thought to expedite the formation of bonds between carers and volunteers and enabled the carers to feel comfortable in showing emotions and sharing difficulties.

Carers feel listened to

Carers described the importance of being listened to by the volunteers. However, this was more profound than simply being listened to in a literal sense. Three subthemes were identified: creating a safe environment; sustaining emotions and helping get through difficult situations.

Creating a safe environment

Carers described the importance of a safe environment, which involved feeling comfortable with and trusting the volunteer with personal information. Some discussed how they felt it was easier to share personal information or discuss difficult issues, such as personal care, on a one-to-one basis as opposed to in a group setting:

Laura. *"...not forgetting that some things are a bit taboo to talk about you know. I can bring it up with (volunteer name) but not so much with the group...I mean some would find it uncomfortable...some of the older ones there perhaps...they wouldn't want to listen to any of that."*

Sustaining emotions

Whilst most carers did not discuss positive changes in any depression or anxiety, they did talk about how befriending and peer support could give them an emotional boost or lift. However, a number of carers stressed that this emotional boost was dependant on the continued support of the volunteer, with some carers drawing attention to the temporary nature of emotional benefits:

Charles. *"...I mean it's nice she's here and all that, but my problems are still here when she leaves again. Perhaps whilst she's here I feel better, but that's it...I feel OK within myself anyway, what with all the support I get elsewhere."*

Another aspect to befriending and peer support which was linked to the sustaining of emotions was expressing thoughts and feelings. Carers referred to this as 'letting off steam', being able to 'sound off' or use the volunteer as a 'bouncing board'

Sue. *"...it's (peer support) been an absolute rock for me and if it hadn't of been for (volunteer name) I don't think I would have been able to cope as well as I have"*

Helping get through difficult situations

Carers talked about ways in which befriending and peer support helped them to get through some difficult situations. This was a result of being able to talk things through with the volunteers in order to learn how to cope with challenging behaviours and being able to see that other carers have experienced similar issues. This sometimes enabled carers to feel more confident in their own caring abilities and to cope better with difficulties:

Henry. *"It sets you up to cope with it a bit better, I think. You don't really want to fight a battle alone, you'd rather win the war with a bit of help...that's what I wanted".*

Someone there just for the carer

The third theme which emerged was how the carers felt that there was someone there just for them as opposed to being there for the person with dementia. Four subthemes were identified: advice and information; personalised support; carers look forward to the support and reduced social isolation.

Advice and information

Carers valued the varied advice and information that the volunteers can provide, viewing them as important resources. They talked about the provision of information regarding specialist local transport organisations, care agencies and other relevant services they or the person with dementia may need to access. Most notably, the importance of volunteers being able to pass on information about potential financial entitlements was highlighted. Carers talked about becoming aware of their benefit entitlements, volunteers helping them to obtain the relevant forms and assistance with form filling:

Wendy. *“She (the volunteer) also mentioned something recently about the benefits I can get...the carers allowance and I’m looking into that now...because I’m a fulltime carer and I wasn’t even aware that I could claim for that.”*

The type of advice and information given varied and carers valued the understanding from volunteers that each situation is different, and that they were able to offer tailored and personalised support.

Personalised support

Part of ‘being there for the carer’ involved support tailored to their individual needs. Carers talked about the importance of flexibility in terms of the frequency of support, with some being comfortable with seeing the volunteer every two weeks as opposed to weekly. Carers and volunteers also often decided between themselves the best way to communicate, with some using telephone and email contact, as well as face-to-face meetings:

Wendy. *“Sometimes email...I mean I know I can call her if I want, I have her number...but email is good so we can arrange where to meet up and if there’s any other things I want to talk about. You know if I do want to meet up with her weekly then she finds the time for me...but generally it’s very flexible”*

Carers look forward to the support

Carers talked frequently about how they looked forward to seeing the volunteer as a result of feeling isolated. Some carers described how they rarely had the chance for social interaction due to their caring role or their own ill health, and that seeing the volunteer gave them something to look forward to. For example, one carer who felt socially isolated

because she was rarely able to leave her house due to her own health issues looked forward to the company:

Mary. *"Oh yes, well I don't get many visitors and as I say I can't get out much...not at my age...not with my leg. So it's nice to see (volunteer name) and I can talk to someone who's been through all this."*

Reduced social isolation

The reduction of social isolation was commonly discussed by carers. There were a number of reasons why carers felt isolated. These included reduced mobility, most of their time being spent on their caring role and family and friends being at a distance. Carers talked about feeling less alone with their problems since receiving befriending or peer support and that they now had someone to turn to, as one carer described:

Henry. *"...I feel part of something, if I've got a problem...rather than just a loner...I suddenly felt as if someone's gathered me in."*

Some carers discussed how, over time, they developed friendships with the volunteers and how this further reduced their feelings of isolation:

David. *"Well obviously I can only speak from my own individual case, but I think we are more friends really, it's not a task where it's a job or a burden for him, I think he enjoys it..."*

Integration of quantitative and qualitative findings

The final phase of the analysis was the data integration of the two types of data. The findings were largely complementary, with the qualitative findings helping to expand on and give context to the quantitative results. This data integration (Table 4) demonstrates how befriending and peer support impacted on carers.

In summary, although little improvements in mental health and loneliness outcomes were observed, qualitative findings illustrated how carers gained emotional support from volunteers, and felt that being befriended or peer supported meant there was someone (the volunteer) was there for them. The statistically significant difference in perceived social support from significant others between baseline and three months was confirmed by

carers taking part in the qualitative phase. Carers described how befriending and peer support can help them be networked into other services, help them cope better with their caring role. This suggests these interventions are an important source of social support for carers of people with dementia.

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Table 4. Integration of quantitative and qualitative findings

| | Quantitative results | Qualitative findings | Data integration | Impact |
|---|---|--|---|---|
| Emotional health | Depression: $p = 0.79$ Anxiety: $p = 0.78$ | <u>Theme: <i>sustaining emotions</i></u> Sue. "...it's (peer support) <i>been an absolute rock for me and if it hadn't of been for</i> (volunteer name) <i>I don't think I would have been able to cope as well as I have</i> " | Qualitative findings support quantitative results in that befriending and peer support had little lasting positive effect on emotional health. It did, however, help to keep carers supported and possibly prevented emotional decline. | Whilst not offering observable improvements in mental health, carers often gained emotional support from the volunteers and they suggested this may prevent emotional decline. However, the support needed to be regular and potentially long-term. |
| Loneliness | $p = 0.19$ | <u>Theme: <i>someone there just for the carer</i></u> Mary. " <i>Oh yes, well I don't get many visitors and as I say I can't get out much...not at my age...not with my leg. So it's nice to see</i> (volunteer name) <i>and I can talk to someone who's been through all this.</i> " | It would be expected from the lack of statistical significance in improvements in loneliness from the quantitative phase (assuming they were lonely to begin with), that carers would report feeling lonely despite the added support. However, carers reported feeling less alone and some had become friends with the volunteers. | Befriending and peer support may not reduce the loneliness carers feel on a day to day basis, but it gave them something to look forward to and they talked about how they found it reassuring that someone was there for them. |
| Perceived social support (from a significant other) | $p = 0.013$ (between baseline and three months) | <u>Theme: <i>carers feel listened to</i></u> Henry. " <i>I feel part of something, if I've got a problem...rather than just a loner...I suddenly felt as if someone's gathered me in.</i> " | Quantitative results showed statistically significant improvements in perceived social support from a 'significant other' between baseline and three months. This was also shown in the qualitative findings, that carers felt they were no longer socially isolated and were supported by the volunteer. | Befriending and peer support are an important source of social support for some carers. Carers received advice and information, were networked into other services, expressed their emotions and talked about their concerns. This can help keep carers supported in the community and enable them to cope better with the challenges of their caring role. |

Discussion

This study has shown that befriending and peer support are perceived as valuable sources of emotional and social support for carers of people with dementia. The development of trusting and empathic relationships was facilitated by the similarity of the carers' and volunteers' characteristics and the shared experience of caring (experiential similarity).

Whilst little measurable positive impact emotional health was found here, other forms of support for carers of people with dementia have demonstrated change (Bunn et al. 2016; Cooke et al. 2001; Sörensen et al. 2006) and have been shown to decrease either reported depression or anxiety. However, the qualitative findings in the present study highlight the importance of carers talking to the volunteers and sharing their feelings, which led them to feel emotionally supported and enabled them to cope with difficult situations and to continue caring. Similar findings have been reported previously, for example with peer mentoring enabling carers to cope with challenges through discussing emotionally difficult topics with volunteers (Greenwood et al. 2013; Greenwood & Habibi, 2014). Therefore, it is argued that befriending and peer support should not replace statutory interventions, but be used to complement them in providing carers with more choice and alternatives to statutory services.

The lack of statistically significant improvements in loneliness are in-line with findings reported by Charlesworth et al. (2008) and also supports evidence by Dickens et al. (2011) that one-to-one social support interventions have limited impact on reducing loneliness. This has also been shown elsewhere with other interventions such as support groups and counselling for isolated older people (Cattan et al. 2005). However, mean baseline levels of loneliness reported here of 49.13 are higher than that reported by Beeson (2003) for carers of people with dementia at 37.35, and higher than the elderly population in general (31.51), (Russell, 1996). This may mean that carers who are experiencing the most loneliness and isolation are more likely to access befriending and peer support services.

The quantitative findings from the current research showed statistically significant improvements in perceived social support from a 'significant other' between baseline and three months. This is an important finding, as previous studies have shown two-thirds of

psychosocial or educational interventions designed for carers of people with dementia do not improve social support outcomes (Cooke et al. 2001). However, this perceived support was not lasting, therefore befriending and peer support could perhaps be offered as short-term interventions (<3 months) and targeted towards those carers who are at greatest risk of becoming socially isolated. Further, qualitative findings showed befriending and peer support were perceived to be an important source of social support for some carers, with many able to express their emotions and talk about their concerns. This was described as largely due to the experiential similarity of the volunteers and is supported by previous research which report similar findings (Greenwood et al. 2013; Greenwood & Habibi, 2014; Keyes et al. 2014; Veith et al. 2006).

Volunteers' experiential similarity was described by carers as aiding in the development of empathy and understanding, highlighting the importance of talking to someone who understood their situation. This has also been shown in previous research, with experiential similarity of volunteers enabling carers to discuss difficulties (Stewart et al. 1998; Sutor et al. 1995), gain empathic acceptance (Veith et al. 2006) and exchange information (Keyes et al. 2014). The current research extends this knowledge, arguing that the mechanisms of experiential similarity are related to 'two-way' sharing of personal experiences between carers and volunteers, and that this builds trust and the development of an environment within which to safely express negative emotions.

Future research should seek to explore at which point in the caring journey befriending or peer support might be most useful to carers. For example, if carers are able to access this support early on after the person they are caring for has been diagnosed, it may reduce the chance of carers reaching crisis. Further, understanding the impact on the person living with dementia by their carers receiving befriending or peer support is needed. Carers in the current research suggested they felt more able to cope with challenges, had improved mood and that this could potentially impact positively on the person they were caring for. Further research is necessary to assess whether these findings are replicable in other locations and in more diverse populations. Finally, exploration of whether social support for carers is most effective given together with the person with dementia, such as with dementia cafés (Greenwood et al. 2017) or on an individual basis should be considered.

Strengths and limitations

A strength of this research is the mixed methods design, which combined the advantages of using both quantitative and qualitative approaches to provide more complete understanding of the processes and impact of befriending and peer support. It also offsets the weaknesses from each method (Mertens & Hesse-Biber, 2012), for example, using quantitative methods alone would not have allowed exploration of which aspects of the support work and which do not from the carers' perspective.

However, the findings need to be interpreted in context of its limitations. The sample size was small and demographically homogeneous; it is therefore difficult to draw conclusions surrounding the impact of peer support or befriending on, for example black and minority ethnic carers. It is also possible that only the most mentally and physically healthy carers were able to take part, with the impact of peer support or befriending on the most socially isolated or emotionally distressed carers remaining unclear. Therefore, further research involving diverse groups of carers would be valuable.

Conclusion

Volunteer led befriending and peer support interventions were found to offer carers of people with dementia emotional and social support, which in turn was reported to enable them to cope better with challenges and continue caring. This can potentially reduce the breakdown of carer mental and physical health and enable them to continue caring. These findings provide promising evidence for health and social care services to consider in funding a range of provision which addresses the social support needs of a growing population of family carers of people with dementia.

Acknowledgements

We would like to thank the carers who participated in this research and the service managers who helped with recruitment. We would also like to thank the Kingston University Research and Investment Fund which funded this research.

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