

Quantifying the benefits of peer support for people with dementia: A Social Return on Investment (SROI) study



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Abstract

Objective: Peer support for people with dementia and carers is routinely advocated in national strategies and policy as a post-diagnostic intervention. However there is limited evidence to demonstrate the value these groups offer. This study looked at three dementia peer support groups in South London to evaluate what outcomes they produce and how much social value they create in relation to the cost of investment.

Methods: A Social Return on Investment (SROI) analysis was undertaken, which involves collecting data on the inputs, outputs and outcomes of an intervention, which are put into a formula, the end result being a SROI ratio showing how much social value is created per £1 of investment.

Results: Findings showed the three groups created social value ranging from £1.17 to £5.18 for every pound (£) of investment, dependent on the design and structure of the group. Key outcomes for people with dementia were mental stimulation and a reduction in loneliness and isolation. Carers reported a reduction in stress and burden of care. Volunteers cited an increased knowledge of dementia.

Conclusions: This study has shown that peer groups for people with dementia produce a social value greater than the cost of investment which provides encouraging evidence for those looking to commission, invest, set up or evaluate peer support groups for people with dementia and carers. Beyond the SROI ratio, this study has shown these groups create beneficial

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outcomes not only for the group members but also more widely for their carers and the group volunteers.

Keywords

dementia, peer support, carers, post-diagnosis support, social return on investment, cost-effectiveness, cost-benefit analysis, value for money, evaluation research

Background

Dementia is a national priority, particularly in the area of diagnosis and effective post-diagnostic support. The increasing numbers of people with dementia present challenges to the health and social sectors in how best to support people following diagnosis. Peer support is routinely advocated in national strategies and policy, such as the National Dementia Strategy (Department of Health, 2009), the Care Act (2014) and National Institute of Clinical Excellence (NICE) quality indicators (2013), and is recognised as a worthwhile community intervention for people with dementia and their carers. Several studies (Clarke et al., 2013; Keyes et al., 2012; Mason, Clare, & Pistrang, 2005) show that peer support can reduce isolation and loneliness associated with dementia and provide information and support on how to manage the condition to live well. People with dementia and their carers routinely say that they draw significant benefit from being able to talk to other people with dementia and their carers and to share practical advice and emotional support, which is shown to improve their overall wellbeing.

Scarcity of public resources means that value-for-money for interventions for people with dementia requires closer scrutiny (Knapp, Lemmi, & Romeo, 2013). Studies suggest that peer support may lead to direct healthcare savings by equipping people with coping mechanisms and providing emotional support, which can lessen the risk of crises and subsequent, potentially avoidable and expensive interventions by the statutory sector (Arksey, 2003; Banerjee & Whittenberg, 2009; Clarke et al., 2013; Hall Long, Moriarty, Mittleman, & Foldes, 2014; Spijker et al., 2009). Traditionally, cost-effectiveness and cost-benefit analyses have been used to assess value-for-money of health and social care interventions. However, the value produced by participating in peer support groups can be subtle and is difficult to measure (Knapp et al., 2013). As such there is a scarcity of research on the wider social, economic or environmental value they create.

Study aim

The aim of this study was to use the ‘Social Return on Investment’ (SROI) methodology to quantify the social value created by peer support groups for people with dementia and their carers.

Methods

Three peer support groups in South London were evaluated in this study (see Table 1). We selected different types of groups, reflecting different models of peer support that are seen within community settings. Groups were selected based on host organisation, funding

Table 1. Group characteristics.

	Independent community, group A	Small local charity, group B	Mainstream national charity, group C
Hours per session	4	2	3
Frequency	Weekly	Fortnightly	Monthly
Average number of participants	23	5	9
Staff involved	A group facilitator, paid staff and 10 volunteers	A group facilitator and one paid staff	A group facilitator, one paid staff and 2 volunteers
Relatives or carers included in the group?	Yes	No	No
Refreshments provided	Refreshments (tea, coffee, biscuits, etc.) and lunch provided for free.	Refreshments (tea, coffee, biscuits, etc.).	Refreshments (tea, coffee, biscuits, etc.) and lunch paid for by members.
Activities provided	A variety of group activities including: reminiscence and music based activities, group games, a chair-based exercise session and occasional manicure and hair dressing sessions.	A variety of group activities and games including memory specific and advice activities.	Group activities, particularly using reminiscence.
Date launched	April 2012	March 2014	February 2012
Funding	Charitable grants and donations.	Local authority and charitable grants.	Local authority.

Table 2. Participant type and data collection method.

Participant type	Data collection method	Number of stakeholders engaged (total number of stakeholders available)		
		A	B	C
People with dementia	Focus group	5 (23)	3 (5)	6 (9)
	Male/female	2/3	1/2	3/3
Carers	Interviews by phone or face to face. Follow up questions via email or phone if needed.	3 (10)	2 (5)	3 (9)
	Male/female	0/3	1/1	1/2
Group staff (unpaid)	Interviews by phone or face to face. Follow up questions via email or phone if needed.	5 (10)	No volunteers	2 (2)
	Male/female	2/3	N/A	0/2

source, group size, group activities and staffing. Groups had to be located in South London and had to have been running for at least one year, so reliable costings and quality of participant data could be collected for the SROI analysis.

This study was a service evaluation and therefore did not require any ethical approval as deemed by the Kings College London ethics committee. Consent forms were obtained from participants prior to involvement.

SROI methodology

SROI has been previously described in detail in the literature (Millar & Hall, 2013). It is derived from better-known analytical methods such as cost-benefit analysis and social accounting and has become a recognised method of measuring impact, outcomes and value created by interventions or organisations. Briefly, through engaging stakeholders (people who it was thought would experience relevant and significant change from being involved with the group) SROI measures the value an intervention creates against the cost of enabling it to occur. It uses a concept of value that goes beyond what can be captured purely in financial terms by incorporating social, environmental and/or economic elements to calculate the total value, hereafter referred to as 'social value'.

The authors closely followed established SROI methodology (Nicholls, Lawlor, Neitzert, & Goodspeed, 2009). The SROI method involves a mixed methods design. Qualitative methods are used to establish which outcomes (themes) were of most importance and impact on participant's lives and ultimately combine to create social value, followed by a quantitative approach to create a monetary representation of these outcomes and their value.

This study used unstructured interviews or focus groups with the stakeholders (see Table 2). Both the interviews and focus groups used open questioning to encourage the stakeholders to talk spontaneously about how being involved with the group impacted them positively or negatively. By allowing them the flexibility to bring forward their thoughts and opinions the risk of interviewer bias was reduced whilst conversational prompts allowed the interviewer to lead or steer the topics under discussion if needed

(Bowling, 2014; Gerrish & Lacey, 2013). With the exception of the members themselves, the other two stakeholder groups, the carers and volunteers, were also asked to comment on how they felt the group affected the other stakeholder groups.

The expectation of sample sizes was modest given the stakeholder population sizes and it was acknowledged that some group members would not be able to be interviewed due to their level of cognitive impairment and that this would reduce the proportion of the member population that could potentially participate. Although a large sample size is not required for qualitative data collection, translation of the qualitative to quantitative data implies that larger sample sizes would have increased the validity of the outcomes for each stakeholder group.

With the help of the group facilitators participants were approached and invited to participate and despite small sample sizes it was felt a level of saturation was met with the themes reported. Group facilitators and volunteers were present at the focus groups for people with dementia to ensure a comfortable and familiar environment for participants. Sessions and interviews were recorded and transcribed verbatim. Transcripts were emailed to participants with email addresses to verify the transcriptions. Group facilitators verified focus group transcripts.

Thematic analysis akin to the 'framework' data analysis approach (Ritchie & Spencer, 1994) identified outcomes for each stakeholder through detecting the key themes in each transcript and charting the number of stakeholders who reported each theme.

SROI makes use of financial proxies to establish the value of themes identified, to enable a market price to be attributed where there is no associated market. We selected proxies that were deemed the closest, most relevant and reflective of a service with a market price. Table 3 shows financial proxies for themes that were evident across all groups. A full list of proxies by each theme is available online (Health Innovation Network, 2015).

Whilst identifying the themes reported by stakeholders was an important objective of this study, the primary objective of an SROI analysis is to create and display a ratio showing the cost of investment (£) of an intervention against the total social value (£) the intervention creates. To establish overall impact the value of each identified cost or theme was multiplied by the number of people reporting that benefit. To avoid the risk of over-claiming, SROI methodology prescribes that specific factors, or considerations are applied to each theme identified (see Table 4).

In-kind contributions

The average UK wage (£14.80 per hour) was used to calculate the value of volunteers' unpaid time with the exception of the accountant of group A, whose known hourly rate was £40 per hour (Office for National Statistics, 2011). The cost of free venue hire for each group was established by averaging the cost of renting out approximately 3–4 other similar venues in each borough.

Our approach

A separate SROI analysis was carried out on each group. By using the same researchers over the same time period, the approach to the method was the same and within this the same perspectives on discount factors, assumptions and financial proxies were used. This maximized the external validity of the three analyses and supported the comparisons then made between them.

Table 3. Financial proxy used to allocate a market price to identified theme.

People with dementia	Financial proxy	Cost
Members experience a reduction in loneliness and isolation	Average unit cost of treating someone with depression (NHS)	£2,414.46
Members are mentally stimulated (including memory stimulation) more so than if they remained at home	Average cost of providing 4 hours of day care centre service, 50 times a year, per person	£1,361.71
Carers		
Carers experience a reduction in stress and burden of care	Average cost of mental health services per individual per year (anxiety and depression).	£1,122.47
Volunteers		
Volunteers have an increased sense of wellbeing through feeling engaged and fulfilled in their role at the group	Value of job satisfaction for 200 hours work (Lambeth = 4 hours × 50 time a year).	£1,804.20
	Value of job satisfaction for 33 hours work. (Croydon = 3 hours × 11 time a year).	£297.69
Volunteers have an increased level of knowledge by interacting with people with dementia and dementia care	Safe & Sound 1 Day Dementia Awareness Course (recommended for professional carers or relatives who look after people with dementia).	£1,074.00

The data methods, analysis and results were validated externally by NEF Consulting of the New Economics Foundation, which is the recognised expert organisation in the UK in using SROI analysis. Full results, calculations and impact maps for each peer support are available online (Health Innovation Network, 2015).

Results

Qualitative findings

Findings from the focus groups and interviews showed that peer support groups gave rise to a number of important themes (see Table 5).

SROI analysis

The SROI analysis showed that the three peer support groups create positive social value that is greater than the cost of investment. The social value created ranged from £1.17 to £5.18 for every pound (£) of investment, dependent on the design and structure of the group (see Table 6). Full results detailing calculations for the impact ratio are available in the Appendices.

Without the valued ‘cost’ of volunteers’ time or the venue hire, the ratios would have been much higher. For example, without the volunteer costs group A’s social value ratio would be £1: £12.99 and group C £1:1.40.

Table 4. Factors considered for calculating SROI impact ratio.

Deadweight	A measure to describe the amount of an outcome that would have happened anyway, even if the peer support group has not taken place, e.g. the theme 'volunteers have an increased level of knowledge about dementia' had a deadweight value of 2% as this is the proportion of the population who are dementia friends and therefore have a higher level of knowledge than an average member of the UK population.												
Displacement	An assessment of what activities or services are displaced by the presence of the peer support group. We found no evidence of displacement as there are a limited number of peer support groups in the three Boroughs for people to access.												
Drop-off ^a	Estimates the future risk of a reduction in stakeholders benefit over a four year period.												
	<table border="0"> <tr> <td>People with dementia</td> <td>95%</td> <td>Carers</td> <td>70%</td> <td>Volunteers</td> <td>50%</td> </tr> <tr> <td>Benefits are experienced whilst people are actively engaging with and regularly attending the group.</td> <td></td> <td>Challenges associated with caring for a person who has deteriorated and unable to attend the group would diminish the benefit faster than that experienced by volunteers.</td> <td></td> <td>Likely displacement from external inputs over the four years, yet it is expected volunteers would retain knowledge and personal value gained from involvement with the group.</td> <td></td> </tr> </table>	People with dementia	95%	Carers	70%	Volunteers	50%	Benefits are experienced whilst people are actively engaging with and regularly attending the group.		Challenges associated with caring for a person who has deteriorated and unable to attend the group would diminish the benefit faster than that experienced by volunteers.		Likely displacement from external inputs over the four years, yet it is expected volunteers would retain knowledge and personal value gained from involvement with the group.	
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Attribution	A measure to consider how much of an identified theme is a result of the group studied or is influenced by external factors, e.g. if participants attend one other peer support or social group which also reduces their sense of loneliness only 50% of the identified theme can be attributed to the group studied.												
Discount rate for net present value	Discounting is applied to values that are projected to last longer than 1 year, based on a rate of 3.5 % (source Government HM Treasury's Green Book) – England's interest rate for 2015.												

(continued)

Table 4. Continued.

Group	Weighting calculation	Weighting value
A	50 sessions per year \times 4 hours = 200 hours per year/24 hours	8.3
B	26 sessions per year \times 2 hours = 52 hours per year/24 hours	2.17
C	11 sessions per year \times 3 hours = 33 hours per year/24 hours	1.38

^aNo previous published data to establish drop off rates therefore we allocated these rates based on knowledge of peer support groups and talking to group facilitators. These assumptions were validated by NEF Consulting.

^bThe average used for the weighting factor was calculated based on frequency of groups delivered by a large charitable sector group provider. Groups run on average 2 hours once a month (a total of 24 hours a year).

Table 5. Themes.^a

For people with dementia	For carers
<ul style="list-style-type: none"> ● A reduction in isolation and loneliness ● A feeling of mental stimulation, including memory stimulation, more than if they remained at home ● An increase in wellbeing from having a sense of purpose and enjoying their time at the group ● A feeling that their sense of personhood and identity is promoted, impacting positively on their wellbeing ● Feeling part of a welcoming community which creates a sense of trust, belonging and social wellbeing ● Feeling fitter as a result of taking part in weekly exercise activities. 	<ul style="list-style-type: none"> ● A reduction in stress and burden of care ● An increased sense of wellbeing through being involved in the group ● A reduction in the feeling of loneliness and isolation. <p>For volunteers that support the groups</p> <ul style="list-style-type: none"> ● An increased sense of wellbeing through being engaged and fulfilled in their role at the group ● An increased level of knowledge by interacting with people with dementia and dementia care ● More transferable skills ● Feeling part of a community

^aThemes in bold were evident across all three groups.

Table 6. Ratio by group.

Group A	Group B	Group C
£1: £5.18	£1: £1.71	£1: £1.17

Discussion

This study has shown that peer support groups for people with dementia, regardless of size or structure, provided personal and social value to people with dementia, their carers and volunteers supporting the group, with a social value ranging from £1.17 to £5.18 for every pound (£) invested.

Common themes were identified across all three groups. A key finding across all groups is a reduction in isolation and loneliness, which is a common outcome seen in peer support generally and for people with dementia specifically (Clarke et al., 2013; Nesta & National Voices, 2015). Our findings show that peer support groups, or having the opportunity to meet others in a similar situation regularly can help people feel less lonely and less isolated and this experience is valued by people with dementia.

The carers of the group members reported observing that the members were mentally stimulated after attending the group, more so than if they had remained at home. Improving or maintaining cognitive stimulation is a recognised aim of some peer support interventions (Spagnolo et al., 2015; Woods, Aguirre, Spector, & Orrell, 2012) to maintain functional ability and quality of life. Studies have shown peer support for people with dementia has a beneficial impact in increasing wellbeing, self-esteem, quality of life and

reducing depression (Banerjee et al., 2003; Leung, Orrell, & Orgeta, 2015), which may delay the need for more intensive support interventions or institutionalisation (Banerjee et al., 2003).

A reduced burden of care through improved coping skills and a reduction in stress has been associated with a reduction in carer depression and improvement in carer wellbeing in several studies (Black & Almeida, 2004; Brodaty, Green, & Koschera, 2003; McConaghy & Caltabiano, 2005). Our study supports these findings, with reduction in burden of care and stress a universal outcome across all groups, demonstrating the positive impact peer support groups have for carers. Findings from interviews with carers from groups B and C showed that these groups offered respite in terms of carers having some time for themselves and peace of mind that their relative is being stimulated and cared for in their absence, which reduced carer stress and the burden of care. Carers who attended group A also reported a sense of respite whilst participating in the group. Additionally, they reported enjoyment in sharing time together in a positive environment and meeting other carers with similar experiences, findings which are consistent with other studies (Greenwood, Habibi, Mackenzie, Dreenan, & Easton, 2013).

For both people with dementia and their carers, the overall sense of improved wellbeing and a reduction in negative risk factors to health such as loneliness, isolation and stress reinforces findings from previous studies (Banerjee et al., 2003; Clarke et al., 2013; Leung et al., 2015; Nesta & National Voices, 2015) that suggest peer support can reduce the risk of reaching a 'crisis point', with people either feeling more able to manage their situation or seek initial support and advice from peers or staff at the group before contacting the GP or emergency services.

Volunteers are not necessarily considered as beneficiaries of a peer support group, but the universal outcome, seen in Group A and C, of an increased sense of wellbeing amongst them is a noteworthy unintentional outcome of these groups. Also of interest is the fact that the volunteers reported an increase in understanding and knowledge of dementia. This outcome could be inadvertently recycled back into the group, potentially leading to improvements in the service being provided at no extra cost and positively influencing the social value produced over time.

All groups demonstrated a higher social value than the cost of investment. However, analysis of the largest group (A) indicates that a more intensive and frequently held group, involving volunteers and carers who also experience benefit, has a large impact on the overall social value produced by the group.

The two groups that had lower ratios show that smaller groups (in design or number of participants) still offer a gain in social value, relative to the cost of the service. People with dementia, like those without dementia, have a variety of preferences in terms of support and socialising and what is appealing to one person in terms of peer support will differ from the next. Our findings support the adoption of a mixed model approach to peer support, demonstrating that groups based on similar structure and design to those evaluated in this study are all a worthwhile investment. However, groups should consider ways to increase the value they create, relative to their investment. For instance, using volunteers as a free resource enables a higher number of people to be supported in the group and thus increases a group's social value directly, as well as indirectly through the positive outcomes experienced by the volunteers. Identifying in-kind contributions such as free venue or activities was shown to increase a group's social value. For example, group A used a communal room in an extra care housing home, with residents invited to participate as well.

Strengths and limitations

A strength of this study is the fact we evaluated three peer support groups of different designs and structures, using a mixed methods approach consistent with SROI methodology. Our methods and analysis were validated by NEF Consulting which is the expert organisation in SROI analysis. Limitations of the SROI process include the complexity of assigning financial proxies to soft themes, for example wellbeing and confidence and the availability of data to be used in robust calculations, for example displacement and attribution values. There is a risk in SROI analysis to focus solely on the ratio without examining the content behind it, which offers a richer insight to the value produced by groups (Nicholls et al., 2009).

Conclusion

The aim of this study was to understand and quantify the social value of peer support groups for people with dementia. A lack of robust economic evidence presents difficulties to commissioners or funders in investing in peer support as an intervention, as well as to groups to secure funding to set up and maintain their service. Findings from this study demonstrate peer support to be a worthwhile investment, both for people with dementia and their carers, but also for the volunteers who support the groups. It demonstrates that independent organisations and initiatives by smaller charities are able to produce a positive social return on investment, just as much or even more than groups run by large, more formal organisations. It provides guidance on how groups can increase their wider social value by using in-kind contributions such as volunteers and cost-free meeting space. We hope this study will aid decision making for those looking to commission, invest or set up peer support groups for people with dementia. Furthermore, we hope to have shown how to use SROI for similar community initiatives that are known to provide benefit but where a monetary value of the intervention is not yet known.

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