

'A lifeline' - the impact of attending stroke groups on stroke survivors and their family carers

Year 1 interim report from Long Term Support Group Model Evaluation

Health Services Management Centre

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1. **Executive summary**

This report summarises the initial findings of an evaluation regarding the development of stroke groups in Gloucestershire in relation to the impact on stroke survivors and their carers. From this research it appears that stroke survivors in Gloucestershire derive significant benefits from being members of stroke groups. These include those that are –

- *practical* (e.g. gaining of knowledge in relation to treatment or services)
- *physical* (e.g. undertaking exercise and improving verbal communication skills)
- *emotional* (e.g. expressing frustrations and concerns)
- *social* (e.g. regaining confidence in a group setting and expanding support networks)
- *motivational* (e.g. to continue to try to regain their abilities and independence).

Carers *gained insight* into their relative's condition and *peer support* in regards to their role as carers. Carers also appreciated the option of *time to themselves* if they chose not to attend along with their relative.

In year 2 of the evaluation we will further explore the impacts on carers, those who attend the network for stroke survivors of working age and people who volunteer in the groups.

2. **Background**

The Stroke Association has been commissioned by NHS Gloucestershire from April 2010 to March 2015 to set up Stroke Groups across Gloucestershire. This is in order to help address the identified local gap in rehabilitative and community support for stroke survivors and their carers. The Health Services Management Centre at the University of Birmingham have been funded to undertake an evaluation of the model over three years from April 2011 to March 2014. This report is a summary of the evaluation findings in Year 1 in relation to the experience of people attending the group and their family carers.

3. What impacts were expected?

The initial stage of the evaluation involved - interviews with staff from the Stroke Association, stakeholders working in statutory health and social care agencies and the co-ordinators of the existing groups. From these interviews and the project documentation we were able to identify the following views regarding the impact of the groups for those who attend and their carers -

- The objectives were that stroke survivors and their carers would move towards more independent living, have greater choice and control, reduced social isolation, better integration into their communities and increased quality of life, confidence and motivation.
- Initial interviews with stakeholders revealed a general (although not unanimous) consensus that the groups have a positive impact through attendees being less isolated, developing confidence in a social setting, gaining emotional support and gathering information and advice. It was thought that attendees would be better able to re-integrate into 'mainstream society'.
- Different views were held by stakeholders regarding the overall purpose and approach of stroke groups – should they be informal, allowed to develop in line with the wishes of the members and have mainly social benefits, and/or should they be more structured and have their principle objectives as being to promote integration within the community and enabling people to 'move on' from the group to volunteering, education and/or employment, and provide information?
- Co-ordinators of existing groups were clear that the main focus of the groups was to provide an opportunity for people to meet socially with other stroke survivors. This was seen as leading to greater social inclusion, a 'lightening' of mood for members and an encouragement for members to 'push' themselves to continue to regain their skills.

4. Methodology

To help understand the type of impacts that might be identified and discuss possible ways to gather the perspectives of group members, the researchers visited an established stroke group in Gloucestershire and canvassed the opinions of members of the on-line stroke network developed for people aged between 18-65.

Subsequently, the researchers undertook focus groups with two additional existing stroke groups and two of the new groups set up recently by the Stroke Association. The topic guide for the focus groups was based on feedback from the initial established group and themes developed from the earlier stakeholder interviews.

The focus groups were mainly composed of stroke survivors but also included family carers who attended the group along with their relative. To broaden our understanding of the specific perspective of carers, additional telephone interviews were undertaken with the carers of participants of two newly formed stroke groups.

Members of the stroke network for people of working age fed back to an initial consultation that they would prefer an on-line questionnaire. However, there were only four responses to this and therefore additional work will be undertaken in Year 2 with the members of the network to capture their views.

5. Findings

5.1 Expectations

Though some participants said they had had no specific expectations of what a stroke group would do for them, where people expressed an opinion, the over-riding sense was that the stroke group would enable them to talk to others who had had similar experiences.

'I wanted to be with somebody else who's been through the same things.'

'It's having somebody to understand as unless you have actually experienced a stroke I do not believe that it is truly possible to understand the physical and emotional changes that one goes through.'

The second main theme to emerge from this line of questioning was the expectation that a stroke group would provide some practical help, whether by improving functional ability through exercise, or other stimuli, or by providing information and advice about their condition.

'Well I thought ... there would be things there to give the stroke patients stimulus and also a good opportunity to speak to other people in a similar situation.'

5.2 Participant perceptions of impact

Participants talked extremely positively about experiencing a range of benefits from their attendance at stroke groups. These included general or none specific benefits such as social contact and developing a sense of a support network, to more focused benefits such as developing a sense of purpose, practising skills and discovering coping mechanisms.

Social contact

For many participants, the opportunity to get together with other people in a social setting to simply chat together was highly valued, regardless of whether they felt there were additional tangible benefits to their attendance. Participants talked to each other about their lives, their past experiences, and their interests and this was found to be of genuine interest. For those people who lived by themselves, the regular contact provided by the group was a means to reduce their sense of social isolation.

'I think it's good socially, it's nice to meet up and ... chat and listen to experiences they've had and ... what they've done with their life. They talk about ...the past and ... it's very interesting.'

'I like everybody so much in the club so I really love to come. Everybody's very friendly...there's a lot of happiness. I live on me own and I've got nobody to talk to, that's why I come here as well. Friendship is important to me and they're all lovely people.'

Support network

Both stroke survivors and their carers talked about feeling very isolated and left on their own after they had been discharged from hospital or the care of health professionals more generally. Stroke groups were therefore seen as a vital resource in terms of developing a support network.

'When xxxx was discharged from hospital, you do feel very much on your own. We didn't have any back-up or support at all.'

'You get a lot of help in the first six weeks or few months that you come out, a lot of teams of people come out and talk to you and everything. That's very nice but then you get left on your own.'

'You're just entirely on your own unless you come somewhere like this – I mean you get physio but very rarely and then you talk to them but they don't have a lot of time to talk about most things, they just want to get on with their jobs.'

Information provision

Participants talked about the stroke group as a source of information, whether through other members, the co-ordinator or visiting speakers. Information could

relate to how to access services, to compare notes on medication and treatment, to ask for advice on diet, or how to overcome specific difficulties. In some instances, participants suggested that there was little information available from alternative, official sources. The stroke groups could therefore be seen as enabling participants to self-manage elements of their condition.

‘One of the things you want to do is to talk to somebody else who’s had one and ask them about what medicines do they take and do you eat this and do you eat that, because other than perhaps the Stroke Association magazine, there’s no help is there otherwise?’

Sense of purpose

The simple act of attending the group seemed to provide participants with a sense of purpose and to act as a motivator to go on and do other things. For others, particularly those who live alone and have limited contact with others, the group was reported by other participants as acting like a lifeline.

‘I know he’s commented on the fact that he finds it very difficult to motivate himself and to get himself out and I think the fact that he’s come here and he’s met other people, I’m sure that that’s been very beneficial to him because he is on his own and he has to be persuaded to come.’

‘It’s a lifeline for a lot of them. I mean there are other elderly people that are on their own at home. It’s a sort of lifeline for them to come out.’

Practising communication skills

For those participants who live alone particularly, the ability to practise their speech was seen as a real benefit. Where speech had been affected quite significantly as a result of a stroke, the group was seen as a ‘safe’ place for participants to practise, as fellow members were considered more likely to be patient and encouraging.

‘It’s very helpful because ... we can’t talk very well... because when you can’t get some of the words out and you know you have something to say, by waiting like me for a while, coming out with what I want to say, nobody outside, they just can’t have any understanding what you’re talking about.’

Sharing experiences and coping mechanisms

This theme generated the widest range of responses from participants. The ability to talk about what had happened to them and what they were going through without embarrassment and feeling awkward about ‘being different’ or the ‘odd one out’

were seen as powerful incentives for participation in stroke groups. In addition, while people wanted to share their experiences in order to know they were not alone, participants were also keen to share their knowledge with others and to pass on tips and advice.

'You automatically do what you're doing and when you talk to somebody they say 'oh, that's a good idea', you know, that's the way we share. It's just different kinds of things that we can show that somebody does and you do everything there and then you can all share things.'

Participants also felt they could join in with all the activities and if they couldn't quite manage something as well as others, it was an opportunity for humour rather than embarrassment.

'Well I just think it's everybody joining in, we're all in the same situation, some things we can do, some we can't, and it's being able to be there and laugh about it because we're all equally in the same boat.'

'When we have the activities it doesn't matter if you can't do it yourself, everybody enjoys doing it because you can laugh because you're doing it wrong.'

Participants also reported that group members were a good source of encouragement for each other, whether to try different things that had worked for them, or whether to motivate them to improve functional capabilities. Hope was also an important coping mechanism for people. People suggested that seeing other members whose condition had improved over time, gave them hope that they might have the same experience.

'When you're with other people it gives you tremendous encouragement and hope that ... you are going to improve and you are going to get better and I think that is so important... to know that there is life at the end of the tunnel... when you see other people going through that and improving, it gives you a lot of encouragement.'

Another important coping mechanism for some participants was the opportunity the groups provided for them to 'count their blessings'. Members talked about feeling more fortunate about their own condition when they could assess themselves as 'being better off than others'.

'I think that's good when you can look and say oh gosh, I'm not half as bad off as he is. I think it makes you feel better. Better, happier. Yeah, thank God I haven't got that, you know.'

Specific group activities

In addition to performing a basic social function, groups were offering participants a range of specific activities, some of which were intended to improve functioning capabilities, whether physical or cognitive, such as exercise sessions, quizzes, or talks from visiting speakers. Some activities also enabled people to try an activity they hadn't tried before which had led some participants to develop a more enduring interest. This was considered of particular benefit for people who had had to give up previous interests as a result of their stroke and the limitations this had imposed upon them.

'Well, I like the exercise ones. We had one early on and we had that for an hour and you knew you'd had it by the time you'd finished... It's Tai Chi, it's the sort of oriental type of exercises... Very, very good for the breathing ... no stress, gentle movement.'

5.3 Carer perception of impact

Carers concurred with the benefits of attendance as expressed by participants, and saw them as addressing key areas of their personal needs connected with being carers. These included - the opportunities the groups provided for time to themselves, if they chose not to attend the session, and conversely for those that did stay, the opportunities the groups gave them to share experiences of caring for a stroke survivor with other carers and deepening their understanding of their relative's experiences.

'... if I need an hour to go and do something on my own it gives me a bit of a break knowing that he's here, you know, being social with other people.'

'I think possibly in all relationships it's good to have time apart anyway, isn't it, like, you don't really want to be living in one another's pockets all the time, do you, and I think a little while apart is good anyway, is my opinion.'

'You get talking and you find out how they cope with things and they point you in the right direction to some of the assistance that they've gone to, for instance, one

person suggested that my husband might benefit from acupuncture and he's actually started a course of acupuncture and it is giving him some help.'

'There is a possibility that in the future I would drop him off down there and go and pick him up at the end, because he doesn't really need me down there, he's, you know, capable of dealing with things himself, it's just that I've found it very interesting at the moment and it's helped me a bit to understand a bit more about the stroke problem.'

6. Conclusion

From this research it appears that stroke survivors in Gloucestershire derive significant benefits from being members of stroke groups. The impacts identified by participants include those that were *practical* (e.g. gaining of knowledge in relation to treatment or services), *physical* (e.g. undertaking exercise and improving verbal communication skills), *emotional* (e.g. expressing frustrations and concerns) and *social* (e.g. regaining confidence in a group setting and expanding support networks). Stroke survivors also reported that the groups were a source of *motivation* to continue to try to regain their abilities and independence. Carers concurred with these benefits for the stroke survivor and also described *gaining insight* and *peer support* in regards to their role as carers. Carers also appreciated the option of *time to themselves* if they chose not to attend along with their relative. The expectations of stakeholders regarding the potential benefits were therefore largely met. Participants saw their attendance at stroke groups as being something that they would do for the foreseeable future and potentially for many years if they continued to derive benefit from the group. This was in contrast therefore to those stakeholders who saw membership of groups as being time limited due their being 'replaced' by other activities such as volunteering and employment.

7. Further information

For further information regarding the evaluation please contact –

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