Groupwork to support self care after stroke

Debbie Neal

Abstract: Stroke is one of the commonest neurological conditions and is the third most common cause of death and the most common cause of severe disability in the United Kingdom. Although risk of a further stroke is particularly high after a Transient Ischaemic Attack (TIA) or first stroke, recent national and local data indicate that patients' and carers' knowledge of stroke and of the lifestyle changes needed to reduce the recurrent risk of stroke is poor and information provision is limited. In addition, patients and carers report that they feel abandoned when they return home and carers are more likely to be depressed than stroke survivors.

ASPIRE, (Acute stroke, Support to self care, secondary Prevention, Information, Rehabilitation & Exercise) is a 12 week roll-on, roll-off post-discharge programme which uses groupwork to provide interactive information provision, individually tailored goal orientated exercise and carer support and aims to enable effective self care after stroke. This article describes the development of ASPIRE and uses preliminary findings from the analysis of interviews with stroke survivors and carers to evaluate the impact of the group and identify areas for further exploration in future interviews.

Key words: stroke; groupwork; rehabilitation

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Introduction

Stroke is one of the commonest neurological conditions, the third most common cause of death and the most common cause of severe disability in the United Kingdom. Although risk of a further stroke is particularly high after a Transient Ischaemic Attack (TIA) or first stroke, recent national and local data indicate that patients’ and carers’ knowledge of stroke and of the lifestyle changes needed to reduce the recurrent risk of stroke are poor and information provision is limited (Stroke Association, 2006). In addition, patients and carers report that they feel abandoned when they return home (Stroke Association, 2006) and carers are more likely to be depressed than stroke survivors (Berg et al., 2005). Although it is well recognised that methods of information provision after stroke need improving (Forster et al., 2005), there is a lack of consensus as to the best way and time to provide that information. A recent study has shown that an individualised information pack (CareFile) has a positive impact on knowledge of stroke at three and six months post stroke. (Lowe et al., 2007). The interactive discussion with patients about the content of the CareFile happened during their inpatient stay so took no account of the change in information required in relation to time post-stroke (Hanger et al., 1998). In addition, with shortening lengths of stay in most acute stroke units there is limited time in which to have those interactive discussions.

Many of the risk and lifestyle factors are the same for stroke and cardiac disease (Gordon et al., 2004). However secondary prevention for stroke is mostly dependent on medication (Rudd et al., 2004) and a recent study showed that significantly more of those with cardiac rather than stroke disease used anti-thrombotic medication in the previous year, had been advised to exercise more and to reduce their fat and cholesterol intake (Cheng et al., 2006). Evidence suggests that vascular risk can be reduced through appropriate self care in cardiac conditions (Lewin, 1998) however there is only limited evidence to support self care in stroke (Jones, 2006). Supported self care, sometimes referred to as the biopsychosocial approach, is where those with long term conditions such as stroke are supported to participate fully in society and care appropriately for their own health. This may be through the provision of information and advice, or the development of skills leading to increased self esteem and confidence and changes in lifestyle or attitude (Chambers et al., 2006).

This article describes the ‘ASPIRE’ (Acute stroke, Support to self-care in stroke and rehabilitation) project.
care, secondary Prevention, Information, Rehabilitation & Exercise) programme which was developed to explore the feasibility and effectiveness of using groupwork to enable effective self care and provide carer support soon after stroke. The programme is then evaluated through analysis of a series of semi-structured interviews with past participants.

‘ASPIRE’: A practice development project

At the time of its development a search of the literature and networking with colleagues via national discussion fora found little published evidence to guide the development of the programme. The programme was set up pragmatically as a pilot project with limited resources and throughout its development has been modified in response to the emerging evidence base and to formal and informal feedback from participants, including audit, focus groups and individual conversations. The ASPIRE programme is held once weekly for both stroke survivors and carers, is run by a multidisciplinary team with expertise in stroke and now consists of a one hour individually tailored group exercise session followed by a half hour interactive information session. In order to enable participants to access it immediately after discharge, the programme uses a roll-on, roll-off format rather than a cohort group plus waiting list.

The interactive information sessions are facilitated by a member of the health and social care team. They are responsive and vary according to need, but the core topics covered are those identified by Young and Forster (2007), that is risk factors (smoking cessation, eating a healthy diet, stress management and medicine management) and life after stroke (getting around - mobility and driving, local services and support groups, mood, cognition and memory, managing relationships and sexual issues, travel and holidays, financial advice, return to work, leisure and new roles). A session on managing medical emergencies including basic life support, which was requested by participants, is also included. In addition, individualised and general information in a variety of formats is available at every session.

Although there was limited evidence to guide the delivery of an exercise programme designed to improve physical fitness after stroke
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(Rimmer et al., 2000; Gordon et al., 2005; Mackay-Lyons & Howlett, 2005; Saunders et al., 2007), the exercise is based on task specific circuit training (Dean, 2000), combines endurance and resistance training (Mead, 2007) and each participant keeps a record of their own circuit. The exercise sessions complement rather than conflict with existing rehabilitation provision and focus on increasing cardiovascular fitness (Ivey et al., 2005; Rimmer & Wang, 2005) and falls prevention (Mackintosh et al., 2005) whilst supporting each individual to achieve their rehabilitation goals (Sabari et al., 2000). In addition to the exercise undertaken at the ASPIRE programme, participants are advised on a home exercise programme and may be signposted to community based exercise facilities, or referred to their local exercise on prescription scheme.

Group members start as soon as possible after discharge home from hospital after their stroke, as it is known that this transition phase is particularly stressful (Rittman et al., 2007) and the risk of a further stroke is particularly high. Participants move on from the group once they have completed approximately twelve sessions, dependent on circumstances and choice, and are then offered either an open or planned follow up appointment. Some past participants have made further contact when new issues arise or with specific queries and other former group members have co-facilitated ASPIRE information sessions.

In order to provide consistency of message around self care, carers are also invited to attend as many of the sessions as they wish. As it is known that carers are more likely to be depressed than stroke survivors (Berg et al., 2005), informal carer support is another element built into the programme. Carers are invited to attend as many of the sessions as they wish. During the exercise session, carers take the opportunity to either take a break or stay to encourage their partners, talk to other carers or the healthcare team for information, advice and support. Many carers also take part in the information sessions though some arrive for a chat at the end of the session or phone for advice between sessions. Responsiveness to individual needs, flexibility and peer support are key principles of the programme.

Participant referral

Anyone who has had a stroke within the previous three months is
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eligible to attend, although, as no transport is provided this does limit or delay uptake in some cases. There have been between four and twelve participants at any one time with an average of eight. The vast majority have been referred directly from the acute stroke unit though some come through the TIA clinic, community rehabilitation teams or occasionally through a General Practitioner (family doctor).

**Participant characteristics**

All those attending the ‘ASPIRE’ programme to date have been able to walk at least a few steps with or without an aid and have had variable levels of upper limb, cognitive and communication impairment. The age range of stroke survivors attending ASPIRE to date has been 28 to 85, with most in their 60s or 70s and the vast majority have been male.

**Evaluation of the ASPIRE programme**

Although evaluation has always been an integral part of the ASPIRE programme, using NHS resources on an unproven service is inevitably unsustainable without more formal evaluation. A multiplicity of competing reasons to evaluate ASPIRE, including proving cost and clinical effectiveness to funders, improving practice for the benefit of group members and demonstrating the value of continuing with the group, led to an epistemological dilemma (MacDermott, 2005). The dominant positivist paradigm would support investigating the effectiveness of ASPIRE in a randomised controlled trial. To ensure the results of such a trial are meaningful it is vital to identify appropriate outcome measures that will measure the impact of ASPIRE on participants. Groupwork, however, is as much about individuals, process and context as about outcomes, which fits better with a qualitative research design. There is also an acknowledged need for qualitative research into improving secondary prevention strategies in stroke (McKevitt et al., 2004). In clinical practice there is often a need to take a pragmatic problem solving approach when faced with a human issue for which there is insufficient evidence to guide practice. Mixed methods research fits perfectly with this pragmatic worldview (Johnson et al., 2007). A key rationale for using a sequential mixed methodological
study is that the qualitative phase supports the development of the quantitative phase. (Greene et al., 1989 cited in Johnson et al., 2007) and places the service users (stroke survivors and carers) firmly at the centre of the research.

Ethical approval was obtained from the local research ethics committee for the following two part sequential mixed methods study which was developed in consultation with previous ASPIRE participants. The objectives of phase one of the study are to identify what, in the view of participants, are the outcomes from attending the ASPIRE programme and also to identify the characteristics of the ASPIRE participants in terms of age, gender, stroke severity, home situation and length of stay in the acute stroke unit. Audio-taped semi structured interviews with previous ASPIRE participants have been used to gather both quantitative and qualitative information (Wengraf, 2001) for phase one of the study, the initial results of which are presented here. Phase two of the study, will attempt to identify which validated measurement tools are able to measure the outcomes identified in phase one, over the twelve week ASPIRE programme.

Participants

Stroke survivors and carers who have attended at least one session of the ‘ASPIRE’ programme starting since November 1st 2007, are able to give informed consent, and able to participate in a taped semi-structured interview have been invited to participate. Those responding to the invitation were sent a participant information sheet and consent form and once the consent form was returned signed, an interview was arranged at a time and venue convenient to the participant. As it is not known what influences outcome in attending the ASPIRE programme, participants have been contacted in chronological order of attendance rather than by trying to gain a representative sample in terms of age, gender, side of stroke or other characteristics. Interviews will continue until theoretical saturation is reached, i.e. new interviews do not bring any new material to the analysis.
Results

To date nine interviews have been carried out, transcribed and initial analysis undertaken; four of these interviews with stroke survivors alone S1, S4, S5 and S7, two with carers alone C1 and C4 and the remainder as interviews with both stroke survivor and carer present S2/C2, S3/C3 and S6/C6 (see Table 1 for the characteristics of the sample).

Emerging themes from the data

Ability to self-care

A key outcome from the ASPIRE programme is increased ability to self-care due to increased knowledge about stroke and secondary prevention. For stroke survivor S3

… the professional chats about things were, were extremely useful … generally, you came away from each session with something. Every session helped in its own small way

and for carer C1

I’ve gained most of the knowledge through the ASPIRE group.

The importance of the carer attending the information sessions as well as the stroke survivor is brought out by C4

I got lots of benefit from that, I was very interested in how many units of alcohol he should drink and what should be his diet and you know about the pills and that, I was interested. It gave me a bit of confidence and a bit of ammunition.

C2 describes how she had found a way of getting her husband to do more exercise

I very cruelly and fairly recently started refusing to get one of his newspapers, I get one, so that he’s got one to, you know, have with his cup of coffee, but he likes two and so I refuse to get it so he has to.
### Table 1
Characteristics of interviewed stroke survivors

<table>
<thead>
<tr>
<th>Gender (m/f)</th>
<th>Age at date of stroke (years)</th>
<th>Civil status</th>
<th>Effects of stroke (stroke survivors). Interviewer's view of health &amp; activity levels (carers).</th>
<th>Time since stopped attending ASPIRE</th>
<th>ASPIRE sessions attended</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1 m</td>
<td>66</td>
<td>Common law husband</td>
<td>Reduced right hand dexterity. Word finding difficulty. Fatigue</td>
<td>5 months</td>
<td>12</td>
</tr>
<tr>
<td>C1 f</td>
<td>-</td>
<td>Common law wife</td>
<td>Fit and well, active retired teacher.</td>
<td>5 months</td>
<td>12</td>
</tr>
<tr>
<td>S2 m</td>
<td>74</td>
<td>Married</td>
<td>Unsteady on feet. Slurred speech.</td>
<td>6 months</td>
<td>12</td>
</tr>
<tr>
<td>C2 f</td>
<td>-</td>
<td>Married</td>
<td>Fit &amp; well, active member of local community.</td>
<td>6 months</td>
<td>12</td>
</tr>
<tr>
<td>S3 m</td>
<td>53</td>
<td>Common law husband</td>
<td>Reduced sensation, dexterity and coordination in right hand. Unsteady on feet</td>
<td>3 months</td>
<td>12</td>
</tr>
<tr>
<td>C3 f</td>
<td>-</td>
<td>Common law wife</td>
<td>Fit and well.</td>
<td>3 months</td>
<td>12</td>
</tr>
<tr>
<td>S4 m</td>
<td>83</td>
<td>Married</td>
<td>Unsteadiness and difficulty walking. Left hand weakness. Slurred speech</td>
<td>5 months</td>
<td>12</td>
</tr>
<tr>
<td>C4 f</td>
<td>-</td>
<td>Married</td>
<td>Active but some health problems. Regularly looks after grandchild.</td>
<td>5 months</td>
<td>12</td>
</tr>
<tr>
<td>S5 m</td>
<td>71</td>
<td>Widowed</td>
<td>Dysphasia, reduced balance and upper limb dexterity.</td>
<td>9 months</td>
<td>14</td>
</tr>
<tr>
<td>S6 m</td>
<td>76</td>
<td>Married</td>
<td>Dysarthria, arm weakness.</td>
<td>10 months</td>
<td>12</td>
</tr>
<tr>
<td>S7 m</td>
<td>46</td>
<td>Married &amp; living with teenage son. Employed.</td>
<td>Reduced balance, coordination and upper limb function.</td>
<td>7 months</td>
<td>12</td>
</tr>
</tbody>
</table>
That increased knowledge was evident even several months after completing the ASPIRE programme; S1 was aware that

Well in my case ... I had this atrial fibrillation. This irregular heartbeat ... and that, that I think brought on my stroke. That’s what caused it.

S3 knew that his stroke was caused by

... a clot in the carotid artery. It went to my brain and stuck somewhere and cut off the all the supply of blood to that part of the brain and killed all the cells.

Carers had also retained their knowledge as C1 illustrates:

He was put on Warfarin. That was to keep the blood thin. To thin the blood or stop it from clotting.

Even more importantly, these gains in knowledge have translated into changes in behaviour (lifestyle and attitude) which have led to measurable health improvements. S3 refers earlier in his interview to how he used to eat a whole packet of biscuits at a time prior to his stroke – his changes in behaviour after the ASPIRE programme are summarised in the following excerpt from his interview:

Well I was absolutely gobsmacked when I went to see the doctor and he gave me the results of the blood tests (for cholesterol) and he just went 3.7 - it’s just amazing. I was thinking well I hope I’ve got it down a bit, you know. You know I was glad to get that down I managed to cut the medication from 40 to 20 mg. Now I actually find the low fat or healthy eating is not bland it actually enables you to you taste the individual item on your dinner plate rather than having it swamped in salt and gravy. I still enjoy the old chocolate and stuff but I’m being more balanced with it.

The ASPIRE programme also facilitated participants' self-efficacy and confidence, an important contributor to ability to self-care (Jones, 2000); as S6 noted:

It was certainly a confidence booster. Being round people you could compare and you got the encouragement from any of the staff there.
The importance of goal setting and the ability to measure progress was identified by a number of interviewees; S3 said

*It's made things clearer in terms of what my goals should be and also not to expect as much, to take it slowly and steadily rather than expecting to, you know, do a few exercises and I'm back to normal.*

S5 explained

*It spurred me on in that way, by seeing the, by measuring the improvement, you could get benefit from that. Yeah it generally gave me goals and it widened my horizons to getting me back to being fit. You know it was stressed, that you've had a knock, a blow, but we're here to help you and I know that I benefited from that.*

The approach taken which avoids a didactic approach was appreciated by S4

*I thought the way it was conducted was very good actually, I had good encouragement but not too many 'do this' and 'do that'.*

As S1 notes building stroke survivor’s confidence is difficult for carers to do:

*I think the ASPIRE group helped me, give me confidence by saying things like you will do these things, you will get better. That was the reinforcing part of it, somebody being encouraging and saying you know...somebody...I mean your wife can be encouraging and say you things that...she doesn't really know. But you get somebody who is in the know and when they say you WILL recover, you tend to rely on that and trust them, and sure enough, you do. .... the physiotherapist and the nurses down at ASPIRE. They know about strokes and they can drive a person onto, onto later recovery.*

The final aspect to self-care is participation in society. As can be seen below, there is tremendous variability in participation levels several months after stroke, even between the seven stroke survivors interviewed to date. This variability is due to a number of factors unaffected by attendance at ASPIRE including impairments, length of
time since stroke and social support network; as S1 said:

Well I was fortunate because I've got a good wife to look after me

and S3 talking about the reduction in his cholesterol levels acknowledged

Yeah that was a hell of an achievement. I couldn't have done that without (partner), she was really helpful

The attitudes of stroke survivors and carers could however be influenced by attendance at ASPIRE and seem to be key to increased participation levels. As S1 says:

I've got so many things I wanted to do and it hits you, you've got this stroke and you think; can I do them? And one side of your brain thinks; 'no you can’t', and the other side of your brain says 'you will do them', and that's what drives you on.

This positive attitude is mirrored by his partner; C1

Everything will take him longer, you know but he achieves wonderful results so I just think he needs a lot of encouragement, and if he gets the encouragement and the praise then he wants to do more. And I think it's practice, it's just to go on doing those things isn't it?

Life is more of a struggle for S3, but he also shows determination to change:

And you know you've had this thing and there's no going back but there's only, you know, you've got to go forward slowly. It's just very frustrating in a way. There are lots of things you want to do but you can't do them. You know you can do them but it's gonna take you ten times as long as it did before. It's almost like the stroke creates a situation where you have to change your personality, the way you behave, because you can't behave like that anymore. You have to stop and think slow down which for me is not easy. I'm a bit of a bull in a china shop. But I'm trying.

Even for S4, who is clearly frustrated by his abilities compared with before his stroke,
At night time, I get tired - I’m not so good on my feet, I do get very tearful.

his attitude is helping him gradually improve as he jokes

My wife doesn’t let me drink so much. I don’t know whether that does me good or doesn’t. But I obey her, I can’t think why, but I do!

The value of the group

Despite heterogeneity in stroke severity, age and gender, the group are unified by the same diagnosis, a clear structure, acquisition of knowledge and skills, mutual support and goals that although individually agreed are often shared. As S7 commented

There’s a group of other people and you’ve got something in common like joined clubs, but I guess it’s got like a club feel about it.

The support from other ASPIRE group members including professionals appears to help individuals cope with the psychological, social and emotional issues inherent in living with a changed body (Ellis-Hill et al., 2000), thereby reducing the isolation. S3 recognised this

You know, I picked up few sort of, some person saying something clicked with me thinking that and just hearing different people’s reactions. It’s talking to other people reinforces the fact that you’re not alone, other people know how you feel and, and it’s good to empathise. If you empathise with the person who’s saying, saying the same things you feel, it gives you a better understanding of how you feel.

Even those apparently taking a passive role, appeared to benefit from the group situation, S2 from watching:

I think with the Aspire group, seeing other people doing things was helpful to me.

and S4 from listening

I didn’t talk much. Other people did. They seemed to have, they were all useful. Probably the best thing to do was, was to, other people having the same trouble.
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I mean...Well you could listen to them. And get their experiences.

The health care professionals were also considered valuable members of the group in conjunction with other participants, as S3 put it.

It was very good, shall we say the professional side of it, of explaining the different aspects of the stroke, what we can do about it, organisations that help, you know there was some good technical stuff and I don't want to, what's the word, detract from it but the actual group chats when somebody would start saying something and everyone would join in or maybe (the health care professionals) would throw out an idea and we'd sort of run it round the group.

Carers found that the ASPIRE group provided some structure and stability, C4:

Because they gave a point to our week for one thing ... as I say it gave a structure to our week.

particularly in a difficult time of transition after discharge from hospital; C1:

The fact that we had a regular meeting to go to when everything was very hard work and not normal. We had a point of contact once a week. It was just a wonderful venue for us to go to when nothing else was fixed at that time.

Some carers embraced the opportunity to socialise; C2

It was nice seeing the same people every week. It became like a little club, you know. Maybe you only just said hello but it was friendly, you know, everybody was friendly.

Not everyone felt the same however, as C4 said

And I think, well it was very obvious, that several of them loved it, you know, chatting it through and...And so forth. I didn’t find talking to old Mrs somebody who’d got a husband who’d got the same kind of thing, no, no, not that, I can see that could be, don’t say, that this isn't any use because our clients aren't getting together and finding any benefit because I'm sure some of them are. But for me personally..... we didn't really find any soulmates exactly, but it was just the general, well, well, the social contact really with you lot (health professionals), more than the other contenders.
For this carer, attendance at the ASPIRE group also provided a break from the frustrating situation of dealing with emotional and behavioural issues (Pierce et al., 2007):

*I didn't have to be here seven days and seven nights without any respite and with a very, very grumpy old thing, who wouldn't do anything I said.* (C4)

None of the carers directly acknowledged that the ASPIRE programme was beneficial to their own mood, however a number of them reported a positive effect on their partners:

*He walked into the gym and he was all smiles.* (C1)

*Although he might have been rather grumpy before he came, he definitely, definitely perked him up mentally and also physically it helped a lot.* (C4)

Stroke survivor S3, explained the effect of attending ASPIRE on his own mood:

*It's just that I think from an emotional point of view and reinforcing and confirming where you are the chatting with other stroke, not victims ... Survivors. You know it helped on an emotional level to pick you up, make you feel right, you know. Where you were doubting what you were feeling, having it confirmed by somebody else sort of reinforced it a bit for you or the way they described it, probably in a slightly different way than you yourself would, oh, I don't know it'd put a different angle on it which enabled you to think through it a bit better.*

S1 also reported a positive impact on his mood:

*I think, it's given me the courage to carry on. It's given me the, how can you say, given me the ... it makes you, it buoys you up. It buoys you up to say there is a future out there, you will get better and you will carry on and do the things...That's what the ASPIRE has done to me.*

Although lacking some of the ‘dynamic forces’ (Northen & Kurland, 2001) such as cohesiveness and strength of relationships that could be formed in a cohort group, many other advantages of groups such as
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peer support remain. Although there is potential for conflict and the group to be ineffective due to weekly changes in membership, there is no evidence that this is an issue for participants to date. It appears there are also advantages to this roll-on, roll-off approach as the group are encouraged and informed by seeing others further on in their journey after stroke, as C1 commented:

There is a chance for you to meet other people who've also had strokes all at different stages to ask questions and get them answered.

Participants are also less likely than a cohort group to compare their rate of progress negatively with others and often seem to provide inspiration as S1 said

Not just in the exercise machine, they were incidental, but the major part of it was maybe to meet others and see how they recover and you think, well if they can recover, I can recover.

Participants also seem less likely to feel a sense of abandonment, already identified as an issue for stroke survivors and carers (Stroke Association, 2006) and recognised that the group had a limited lifespan and that there was a time to move on. As one carer succinctly put it:

You need it and then it gives you what you need and then you kind of, you graduate from it. (C1)

Discussion

Seeking the views of service users in the development of new services has recently become higher profile (Darzi, 2008). However evaluation of groups through seeking participants’ views has long been recognised as good practice though these evaluations are rarely published (McDermott, 2005). A key aspect to the ASPIRE programme is the inclusion of individuals who are often excluded – those with some communication and cognitive impairment. Although time-intensive, use of semi structured interviews has also allowed the participation in the research evaluation of those with communication difficulties (van
To date, relatively few interviews have been carried out and these have included only those who have completed the ASPIRE programme, so no information is available on why people have chosen not to complete the programme. Unfortunately, none of this group, though invited to, have so far agreed to be interviewed. In addition, all of the stroke survivors interviewed have been male and all the carers female which although in part could be due to the vast majority of participants being male, could also significantly bias the findings.

Two main themes emerge from the data analysed so far: the first is the value of the ASPIRE programme in supporting self care after stroke. Despite being developed before the publication of the common core principles to support self care (Skills for Health, 2008), the ASPIRE programme is in line with all these principles. The second theme is the importance of the other group members to the programme – they are regarded by most as integral to the process. This is in marked contrast to a study published this year (Lennon et al., 2008) in which stroke survivors attended a ten week programme of twice weekly exercise plus two stress management classes. Although this programme led to improvements in cardiovascular fitness, cardiac risk score and self reported depression, this medical approach had participants exercising in pairs so made very little use of group interactions. There are also a number of sub-themes, which may become more significant with future interviews, including providing structure, stability and continuity at a time of uncertainty and also giving a sense of future and hope.

At this stage in the evaluation it is apparent there are a number of aspects to the ASPIRE programme that need further exploration in future interviews. Firstly although ASPIRE seems to have a positive effect on aspects of secondary prevention such self efficacy and knowledge of lifestyle changes, another key aspect of secondary prevention is medication adherence. Many ASPIRE participants have had their medication monitored and appropriately adjusted by the prescribing stroke nurse consultant in order to increase effectiveness and reduce side effects, however interviews to date have not identified whether this has supported increased medication adherence. As it is known that the 65-79 age group, with no pre-stroke disability which describes the majority of ASPIRE participants, are less likely to persist with medication than those over 80 and / or with previous disability (Lummis et al., 2008), this issue
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Secondly, although attending the ASPIRE programme appears to have a positive effect on stroke survivors' mood and self esteem, the effect on carers' mood is unclear. With only two individual interviews with female carers to date, there is limited data to identify other issues for carers such as gender (Larkin, 2007), although observation suggests that male carers also benefit from participation though sometimes gaining support from male stroke survivors rather than female carers. The impact on participation also needs further exploration, although it is anticipated that attendance at ASPIRE will enhance participation due to a reduction in emotional distress (Cardol et al., 2002).

The final and most important factor is how to maximise the effectiveness of the group interactions (Carson & Hopkinson, 2005). The author and colleague who organise the ASPIRE programme have always sought to facilitate group interactions rather than lead the group, for instance by making the information sessions interactive rather than a lecture and by introducing new ASPIRE participants to existing participants with whom they may share common interests as opposed to just being a fellow stroke survivor. It is hoped that future interviews will give more insight into how the ASPIRE group works which will enable it to be run elsewhere. Stroke survivor S3 has already shared some ideas about how best to support the group processes.

It needs to be controlled; you need a, what do you call it? Somebody to...facilitate, to keep control of it, don't let it wander too far. You know 'cos sometimes you know, you know maybe a natural subject that you brainstorm or you start discussing eventually it's going to start to branch off into other directions, and you want to try and keep it within the.....you know you're just there to sort of say okay look, what do you feel about, you know, the fact that you have trouble talking now and everybody discusses it. And you could, you know, the professional can throw in observations that would enable the, you know, the, let people be more aware of what they're discussing.
Conclusion

The ASPIRE programme is a practical and pragmatic approach to supporting those with stroke and their carers in the early stages after stroke. Participants’ views are that it promotes improvements in mood, confidence and the ability to self care and also that the group is essential to the process. The ongoing qualitative evaluation will continue to analyse the components of that group process and the skills needed to facilitate that process.

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