

Post-stroke peer-support groups Research report

An investigation of the Stroke Association's peer-support groups before and during the Covid-19 pandemic

Mark Tarrant, Ruth A. Lamont, Laura Hollands, Luke Mounce, Sarah G. Dean, Chris Code, Jess Bollen, Amy Sanders & Raff Calitri

April 2022

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Executive summary

Stroke is one of the leading causes of serious long-term disability among adults. Stroke survivors may be left with not only physical impairments, but also language and other cognitive problems, lethargy, emotional lability, depression and anxiety. These outcomes can have major implications for day-to-day functioning and psychosocial health, including difficulty in the ability to form and maintain new and existing relationships, an increased likelihood of social isolation and loneliness, low self-esteem, and reduced wellbeing. Post-stroke support is therefore essential for many stroke survivors to ensure that they can adapt and continue to live as well as possible with the long-term consequences of their stroke.

The United Kingdom's main provision of long-term post-stroke support is the Stroke Association's 200+ peer-support group programme. Prior to the Covid-19 pandemic, these groups offered stroke survivors an opportunity for social connection and involved a broad range of activities for members. Previous research into the peer-support programme highlighted several potential benefits that stroke survivors could derive from participating in a group.

The current project sought to further understand the role that these groups play in the lives of stroke survivors. Our evaluation of the peer-support programme addressed the question of *how and why post-stroke peer support groups might benefit stroke survivors*. We used mixed methods to answer this question, including two large quantitative surveys (total of 839 respondents from 118 separate groups) and a series of interviews (20 respondents) with group members and volunteer leaders. Through these research activities, we documented stroke survivors' levels of loneliness and wellbeing, as key indicators of their psychosocial health. We also explored a hypothesised mechanism by which participation in a peer-support group impacted psychosocial health: in particular, we investigated stroke survivors' sense of *social identity* as group members and explored how this was related to loneliness and wellbeing.

We originally planned to conduct the survey at two time points in order to document how experiences of the peer-support groups, and resulting health outcomes, may change over time. However, the global Covid-19 pandemic started shortly after completion of the first survey. The interruption that the pandemic caused to the operation of the peer-support programme meant that we had to modify the project focus. However, it also presented us with an opportunity to develop valuable insights into the impact of the pandemic on stroke survivors' experiences of the peer-support programme.

Specific findings from the project are summarised below and elaborated in this report.

Summary of main findings

Pre-pandemic survey

- 116 group leaders (out of 215) distributed a survey amongst their groups. 579 participants responded from across 84 groups.
- 47% of participants reported often feeling lonely. This is higher than loneliness in the general population, where 19% of people aged over 50 report often feeling lonely.
- Participants reported similar levels of wellbeing to the national population.
- Social identity as a member of a peer-support group, social support, and sense of connection to the group were each associated with lower levels of loneliness. Social identity, connection to the group, social support and autonomy were associated with higher wellbeing. These findings indicate that group participation may offer a means by which stroke survivors can manage their psychosocial health.
- Social identity was also associated with variables reflecting stroke survivors' *psychological readiness* to engage with a group (e.g., sense of self as a stroke survivor, having multiple other group memberships) and *group structure* (e.g., meeting frequency)

Pandemic survey

- 260 participants responded from 118 groups with a further selection of group members and volunteers participating in a telephone interview.
- Levels of loneliness in the pandemic survey were similar to the pre-pandemic survey, with 44% of respondents reporting often feeling lonely.
- Wellbeing scores between the pre-pandemic and pandemic samples were comparable, as were scores for social identity as a peer-support group member.
- Stroke survivors indicated a high level of resilience and adaptiveness during the pandemic; 87% of group members had some form of contact with their groups within three months of in-person meetings being suspended.
- Main contact methods for the groups were telephone calls, emails and text-based messaging. These adaptations enabled group members to (re-)interact with other members, sustaining their sense social connection to the group.
- Interviews with stroke survivors further illuminated the value of being a member of a peer-support group. Respondents talked about how their shared experience and understanding from the groups was key to their positive experience of the group. These experiences appeared especially marked during the pandemic when face-to-face group interaction was not possible.

Key Messages

- This national survey documented stroke survivors' experiences of the Stroke Association peer-support groups prior to and during the early stages of the COVID-19 pandemic.
- Stroke survivors who participated in this study reported higher levels of loneliness than the general population but broadly similar levels of wellbeing. Notably, these levels appeared to be consistent between the pre-pandemic and pandemic surveys.
- Participation in a peer-support group appeared to enable stroke survivors to manage their psychosocial health. Specifically, we saw that members' sense of social identity as a group member was associated with experiencing the group as a resource for social support, a sense

of group connection, and these experiences were also associated with their psychosocial health (specifically, loneliness).

- The findings indicated that more frequent contact with a peer-support group (i.e., about once a week), regular attendance at group meetings, and having contact with broadly the same individuals each time was important. Supporting groups to meet frequently and encouraging members to attend as many sessions as possible may help provide a stable environment and sense of group continuity amongst the members, and in turn enable stroke survivors to better manage their psychosocial health.
- While some factors impacting individuals' readiness to engage with a peer-support group cannot be modified (e.g., seeing oneself as a stroke survivor), structurally it may be possible to organise the groups in a way which makes it easier for group members to develop a shared social identity, as noted above. Additionally, facilitators should be alert to the possible (negative) impact of new members on the existing group atmosphere and consider how to effectively integrate these within the group. One suggestion might be to pair up new members initially with established, well-networked members (so-called 'connectors') within the group.
- Data from both the survey and interviews suggested that groups were adaptive/reflexive to the suspension of face-to-face meetings. Although contact with group members during the pandemic was well received, the contact primarily involved telephone calls from a group leader on a one-to-one basis. Going forward, the Stroke Association may wish to extend and formalise contingency plans that were developed *in response* to the pandemic so that group leaders across the network can ensure maintenance of contact *between members* during periods that are understandably disruptive for the individuals concerned.

Introduction

Stroke is one of the most common causes of serious long-term disability in adults¹. The challenges arising from stroke include physical and cognitive impairment, communication difficulties, chronic fatigue, emotional lability and post-stroke depression and anxiety²⁻⁶. This may lead to problems in day-to-day functioning, but also disrupt work and relationships. Stroke survivors may be at greater risk of experiencing both worse social (e.g., social isolation and loneliness) and psychological (e.g., low self-esteem, confidence and wellbeing) health outcomes⁷⁻¹¹.

In response to the health challenges presented by stroke, the Stroke Association (SA) established a five-year national programme which sought to increase the number of post-stroke peer-support groups available to stroke survivors from 127 in December 2015, to 240 by March 2021¹². These peer-support groups are commonly run by volunteers – ‘peers’ – who have experienced a stroke themselves or who care for/have cared for someone who has¹³. Groups aim to provide a basis for stroke survivors to meet and socialise, and they are often organised around activities such as the arts, talks, physiotherapy and days out. It is intended that through participation in a peer-support group, stroke survivors will see improvements in the psychosocial health outcomes that present a significant challenge to the lives of many¹³⁻¹⁵.

In 2015, the Nuffield Trust conducted an evaluation of the SA’s peer-support programme¹³. This involved questioning more than 200 stroke survivors, 100 carers and 20 SA volunteers and staff, using surveys and interviews. The evaluation highlighted several potential benefits of participation in the peer-support groups with respondents reporting feeling positive about being part of a group, and also that their confidence, social networks, health and wellbeing benefitted from group participation¹³.

The findings of the Nuffield evaluation align with a broader evidence base, beyond stroke care, that demonstrates the potential health and wellbeing benefits of participation in social groups¹⁶⁻¹⁸. However, relatively little is understood about how and why peer-support groups may bring about these positive effects. For example, how does participation in a peer-support group impact on stroke survivors’ sense of ‘self’, or *social identity* that they share with others, and resulting feelings of social connection to the group and its members? And how might these experiences shape the health benefits of participating in a peer-support group? Answering these questions can potentially help inform and improve stroke support going forward, and to answer them we drew on a body of research called the ‘social identity approach to health’.

The social identity approach to health

‘Social identity’ refers to an individual’s sense of self that is derived from their group membership(s)¹⁹²⁰. The social identity approach to health starts from the observation that, because it is a basis for meaningful group life, social identity fundamentally shapes the cognitions and behaviours that impact health outcomes²¹. Essentially, the approach describes the social and psychological processes that play an important role when people come together in a group. More specifically, the approach details the *psychological resources* that become accessible when group members socially identify with the group – that is, when they see themselves *as group members*. These group-based resources include increased *connection* to group members, stronger *social support*, and greater *autonomy* (or self-efficacy): see Box 1. The approach has an extensive evidence base: a recent review has established social identity as key mechanism underpinning the impact of group membership on different health outcomes, including depression, anxiety, stress, quality of life, self-esteem and also physical health. As well as helping to explain the health effects of participation in a social group, the social identity approach to health has translational utility by offering insights into

how group programmes can be organised and delivered to help ensure the intended health benefits are realised.

Drawing on the social identity approach to health, a focus of the current project was on the social identity 'potential' of the SA stroke-support groups. That is, the project investigated stroke survivors' experiences of the support groups in terms of their social identity *as group members* and considered how the resources associated with this social identity related to health outcomes.

Recognising the importance of social identity in shaping health, a second focus of the project was on factors that may contribute to, or explain, stroke survivors' sense of social identity with their peer-support group. We considered two pertinent processes, one psychological and one structural:

1. Psychological readiness: Some people may just be more psychologically 'ready' and open to engaging with social groups. Factors such as a person's previous participation in groups, whether they have joined groups post-stroke, already knowing someone from the group, and seeing themselves as a stroke survivor (identity centrality), are examples of factors that may 'ready' someone to identify with it^{22 23}.
2. Structural set-up of the group: There are several structural aspects of a group that may determine its potential to create an environment for members to develop a (positive) social identity²⁴. Here, we looked at two of these: (1) how often the group meets and (2) whether the group consists of the same people at each session (group continuity).

Box 1: Psychological resources accessed when group members share a social identity

Connection: Stroke group members have reported in previous interviews that forming meaningful social connections with others who had similar health experiences is a key benefit of going along to stroke groups^{25 26}. Such reports resonate with findings from other research where people with a variety of chronic health conditions have talked about the broad benefits of social identity²⁷. We therefore expected that respondents who identify with the peer-support group would be most likely to report feeling connected to the group and, accordingly, to trust and to share experiences with others in the group^{21 22}.

Social support: By identifying with a group and connecting with other group members, individuals are likely to experience the group, and the people in it, as supportive^{21 22}. Feeling supported in this way may contribute to group members' ability to navigate pertinent intra- and inter-personal changes that are commonly experienced post-stroke. Research has indicated that social groups provide a range of practical and emotional support that helps stroke survivors and those with other chronic illnesses to cope^{11 27 28}. For example, groups have been described as helping stroke survivors to normalise their experiences after stroke, enhancing feelings of being understood by others, as well as acting as a space for acquiring understanding and practical knowledge^{9 11 25 26}. Social support after stroke is linked to better functional and psychological health^{11 29}.

Group autonomy: Self-efficacy – defined as how strongly people believe they can cope with situations³⁰ – is also important for wellbeing³¹. Loss of functioning and independence experienced by many stroke survivors may be damaging for self-efficacy, and some stroke survivors may struggle to regain this. Participation in a group, and identification with it, offers a potential means through which stroke survivors can re-gain a sense of self-efficacy^{22 32}.

Project overview

The initial aim of the project was *to establish how and why stroke survivors come to benefit from their participation in stroke groups*.

When the project began in 2019, there were more than 200 SA peer-support groups meeting face-to-face in the UK. The project intended to survey the experiences of members in late 2019/early 2020 and again a year later in order to gain some insight into what factors were associated with

changes in members' health outcomes (for example, the progression of loneliness over time). The global Covid-19 pandemic prevented the administration of the second survey due to the suspension of face to face group operations from mid-March 2020³³. However, the pandemic raised new questions about the running of SA groups in the absence of face-to-face contact.

The wider research community has begun to document the negative impact of the pandemic on the wellbeing and social connectedness of those with different chronic health conditions³⁴, and some early data on stroke survivors has indicated that many people have been negatively affected by the pandemic, including stronger feelings of depression and anxiety at least its early stages³³. Recognising this, many leaders of the SA peer-support groups set-up remote forms of contact so that group members could continue to stay in touch with their stroke group even when unable to meet face-to-face. We modified our research plan in order to consider members' experiences of this change and develop insights into how the peer-support programme might support stroke survivors in the future, particularly in contexts where in-person contact may not be possible. Specifically, during the Covid-19 pandemic, we focused on the following questions:

1. How did SA peer-support continue and maintain contact with their members during the pandemic?
2. How did group members' experiences of their group during the pandemic relate to wellbeing?

Research Objectives

1. To identify how and why post-stroke peer-support groups benefit stroke survivors (pre-pandemic)
2. To explore how SA peer-support groups have maintained contact with members during the pandemic
3. To investigate how experiences of the peer-support groups relate to members' loneliness and wellbeing during the pandemic

These objectives were addressed using multiple methods, including survey-based questions (with closed and open-ended questions); telephone interviews using semi-structured open-ended questioning to explore experiences more deeply. Ethical approval for the project was provided by the University of Exeter College of Medicine and Health Research Ethics Committee, ref: Oct19/B/223).

Pre-pandemic Survey

Methods

From October 2019 all UK SA group leaders were contacted. Group leaders were asked to distribute paper-based surveys to members during one of their regular meetings. All attending stroke survivors (member or volunteer) aged 18+ were eligible to complete the survey.

The SA groups vary in size, frequency of meeting and activity focus (e.g., social, activity-based, such as art or exercise, or specifically for people with speech and language difficulties). An opportunity sample was recruited in order to involve as many stroke groups and members as possible.

Questionnaire data were collected during January – March 2020. Group members were informed of the study and given an information sheet at least one week before the survey was distributed during a group session. Participants with communication difficulties completed an 'aphasia friendly' version

of the survey set out in accordance with SA guidelines³⁵ - visual cues were provided alongside simplified, larger text highlighting key messages.

Participants provided written consent prior to completing the survey. The survey contained a series of demographic questions alongside measures of group process and measures of psychosocial health. The full list of measures and a copy of the questionnaire is available from the authors upon request. Here we report on the measures and outcomes most pertinent to the above research objectives. For demographics, participants reported their age (in years), gender (male, female, non-binary), living arrangements (alone or with others) and time since their first stroke (<1 year, 1–2 years, 3–5 years, 6–10 years or >10 years). Subjective health was assessed using the item ‘*Please rate your overall health*’ and answered as either Poor, Fair, Good or Excellent. Several group demographics were also measured, including the participant’s role within the group (volunteer or member), and the number of sessions attended. Alongside the demographic measures the survey contained the main measures of focus which related to i) structure of the groups, ii) individuals’ readiness to identify with the group, iii) group processes, and iv) psychosocial outcomes. A summary of these measures can be seen in Table 1. All measures were constructed such that higher scores indicated higher values on that particular measure (i.e., higher scores indicated greater loneliness, higher wellbeing, a stronger connection to the group, etc). Individuals did not have to complete the questionnaire if they did not wish to.

Table 1 - Outcomes measured in pre-pandemic surveys

Measures	Example question/s
Psychosocial Outcomes	
UCLA Loneliness scale ³⁶	3 questions (e.g., ‘How often do you feel that you lack companionship?’) on a 3-point scale (1=‘Hardly ever’, 2=‘Some of the time’, 3=‘Often’)
Shortened Warwick-Edinburgh Well-being Scale (SWEMWBS) ³⁷	7-items (e.g., ‘I’ve been feeling relaxed’) on a 5-point scale (1 = ‘none of the time’ to 5 = ‘all of the time’)
Group Processes	
Group identification Scale ³⁸	4-items (e.g., ‘I feel a bond with my group’) on a 5-point scale (0= ‘completely disagree’ to 5= ‘completely agree’)
Connection	‘We come together well as a group’ rated on a 5-point scale (from 0= ‘completely disagree’ to 4= ‘completely agree’)
Group autonomy ³⁹	‘We are able to influence the sessions and activities of the group’ rated on a 5-point scale (from ‘0= ‘completely disagree’ to 4= ‘completely agree’)
Oslo Social support Scale ⁴⁰	3-items (varying scales; e.g., ‘How easy is it to get practical help from the people in the group if you need it?’)
Psychological readiness	
Previous participation in groups ⁴¹	‘Before my first stroke I belonged to lots of different groups (e.g., hobby/interest groups; work groups etc.)’ rated on a 5-point scale (from 0= ‘completely disagree’ to 4= ‘completely agree’)
Knowing other members before joining	‘Did you know any other members of the group before you joined?’ (1= ‘yes’ or 0 = ‘no’)
Post-stroke group membership ⁴¹	‘After my first stroke I have joined one or more new groups’ rated on a 5-point scale (from 0= ‘completely disagree’ to 4= ‘completely agree’)
Identity Centrality	‘I often think about the fact that I am a stroke survivor’ ⁴² scored on a 5-point Likert scale, from 0= ‘completely disagree’ to 4= ‘completely agree’.
Structural Measures	
Group set-up- How often the group meets	0=‘Weekly’, 1=‘Fortnightly’, 2=‘Monthly’, 3=‘Other’
Group continuity	‘Do the same people come to each session?’ scored on a 5-point scale (0= ‘never’, 1= ‘rarely’, 2= ‘sometimes’, 3= ‘often’, 4= ‘most of the time’)

Data Analyses

Where a response option contained less than 10% of responses, response categories were merged - for the group process measures, all single item measures were dichotomised to “completely disagree/Disagree/Neither agree nor disagree” and “Agree/completely agree”, except for the measure of connection which was dichotomised to “Completely disagree/Disagree/Neither agree nor disagree/Agree” and “Completely agree”.

Descriptive data are summarised here using mean values and percentages where relevant. Statistical models known as multilevel regression modelling were used to account for the clustered nature of the data (because we were looking at outcomes for individuals within groups). All group process predictors (social identity, group autonomy, connection, and social support) were highly correlated with each other (see appendix A). As such each measure was entered into a separate multivariate model for each psychosocial outcome (i.e., four separate logistic models for wellbeing and four separate linear regression models for loneliness), to provide estimates adjusted for demographic covariates (factors that are also known to impact the outcomes). Only covariates that had a bivariate relationship with the psychosocial outcome were included in the regression models. Due to the exploratory nature of this research, many comparisons were made. Results were not corrected for multiple comparisons, and findings should be interpreted in light of this.

Results

The survey was completed by 579 stroke survivors; 446 people completed the standard questionnaire and 133 completed the aphasia-friendly questionnaire. These responses represented 84 peer support groups across England, Scotland, Wales and Northern Ireland, with between one and 25 questionnaires completed per group (the median number of questionnaires completed per group was six). Note that the SA does not keep official membership records so it is not possible to report overall response rate for the survey.

Descriptions of the participants are shown in Table 2a. Stroke survivors were on average 68.6 years old. Mean loneliness score was 5.23, with 47% reporting often feeling lonely. This is higher than loneliness in the general population, where 19% of people aged over 50 report being often lonely⁴³. Participants had an average wellbeing score of 21.93 out of 35, similar to the national population mean of 23.6⁴⁴. Note that scores lower than 20 indicate possible depression or anxiety. Stroke survivor identification with their peer support group was high, with a mean score of 3.33 (out of 4). Most stroke survivors had been a member of their peer-support group for over 12 months (76%) and attended every, or nearly every, session (79%). Peer-support group characteristics are shown in Table 2b; most were classed as general support groups (68%), with “Speakability” or aphasia groups being the second most common group type (16%).

Table 2a Participant characteristics (pre-pandemic)

Respondent characteristics	
Number of respondents (n)	579
Age (years), mean (SD)	68.6 (11.0)
Gender, n (% female)	263 (45.6)
Role in the group, n (% volunteer)	125 (21.6)
Questionnaire version completed N (%)	
Non-aphasia	446 (77.0)
Aphasia	133 (23.0)
Living arrangements, n (%)	
On my own	172 (30.6)
With family	365 (64.8)
With non-family	10 (1.8)
Residential / nursing home	4 (0.7)
Other	12 (2.1)
Time since stroke, n (%)	
<1 year	42 (7.5)
1-2 years	91 (16.2)
3-5 years	171 (30.5)
6-10 years	130 (23.2)
>10 years	127 (22.6)
Overall health, n (%)	
Poor	39 (7.0)
Fair	240 (43.1)
Good	239 (42.9)
Excellent	29 (7.0)
Time in stroke group, n (%)	
Less than 1 month	13 (2.3)
1 – 2 months	19 (3.4)
3 – 6 months	58 (10.3)
7 – 12 months	44 (7.8)
Over 12 months	428 (76.2)
Group attendance frequency, n (%)	
None, or almost none	7 (1.2)
Less than half	12 (2.1)
About half	13 (2.3)
More than half	87 (15.1)
Every, or nearly every	457 (79.3)
Before my first stroke I belonged to lots of different groups, agree N(%)	423 (75.5)
After my first stroke I have joined one or more new groups, agree N (%)	412 (73.57)
I often think about the fact that I am a stroke survivor, agree N (%)	313 (56.2)
Measures	
Loneliness mean (SD)	5.23 (2.0)
Loneliness, often lonely N (%)	195 (46.8)
Wellbeing mean (SD)	21.93 (4.8)
Group Identity mean (SD)	3.33 (0.6)
Social Support mean (SD)	64.37 (22.3)
Group Autonomy N (%)	429 (75.9)
Connection N (%)	366 (64.6)

Percentages will not always equal 100 due to missing data

Table 2b Table of stroke peer support group characteristics (Pre-pandemic)

Group characteristics (Groups N =84; participants N=579)	
Group meeting frequency	N (%)
Weekly	306 (52.9)
Fortnightly	134 (23.1)
Monthly	122 (21.1)
Other	17 (2.9)
Group location	N (%)
C1-C2	176 (30.4)
N Ireland	32 (5.5)
N1-N4	153 (26.4)
S1-S3	162 (28.0)
Scotland	11 (1.9)
Wales	45 (7.8)
Activity	N (%)
Social Support	429 (74.1)
Speakability / Aphasia	65 (11.2)
Exercise	6 (1.0)
Singing	8 (1.4)
Creative Arts	30 (5.2)
Stroke Cafe	31 (5.4)
Other	10 (1.7)

The role of group processes on psychosocial outcomes

Loneliness: Social identity, social support, and connection were significantly negatively associated with group members' levels of loneliness. That is to say that as group members' identity with the group increased, as their social support from their group increased, or as their connections to their group grew stronger, there were reductions in reported loneliness (the detailed regression models can be seen in appendix B).

Wellbeing: Group processes were significantly positively associated with wellbeing. Increases in social identity, connection, social support and autonomy all were associated with increased wellbeing (see appendix C).

Factors affecting identification with the stroke group

A series of univariate regression models explored whether group members' 'psychological readiness' and 'group structure' variables were associated with social identity. For *psychological readiness*, identity centrality as a stroke survivor and having many post-stroke group memberships was positively associated with social identity as a member of the peer-support group. For *group structure*, having the same people come to each session (group continuity), being a member of the group for 12 months or longer, and attending every or nearly every session, and more frequent group meetings, were positively associated with stroke group identification (see appendix D).

Summary

From a sample of almost 600 group members from across 84 peer-support groups, this survey provides a detailed summary of psychosocial health amongst stroke survivors in the UK. While caution should be exercised in interpreting the study findings (we cannot know how representative responses are of the wider population of peer-support group members), around half of the survey respondents here reported feeling lonely, and levels of loneliness were higher than those observed for non-stroke survivors. However, wellbeing amongst the respondents was found to be broadly similar to that observed in the general population. While we have no comparable data from stroke survivors who did *not* attend the peer-support groups, it may cautiously be speculated that participation in the groups offers a means by which stroke survivors can manage their wellbeing.

Our analysis of the group process variables supports this interpretation: here, we observed a clear relationship between members' social identity *as a member* of the group (and related group processes) and their levels of well-being and loneliness.

Our analysis also addressed important questions about 'when' and 'for whom' participation in the groups might impact health. Here, we found that stroke survivors' sense of social identity *as members* of the peer-support group was associated with a number of variables, both those reflecting psychological readiness (sense of self as a stroke survivor, having multiple other group memberships) and structure of the group (meeting frequency, attendance frequency, group continuity, and being more established as a member over time). We discuss these findings in more detail in the discussion.

Pandemic Survey

As noted earlier, the Covid-19 pandemic prevented us from progressing the original research plan to explore the longitudinal (over time) relationships between group processes, structural variables, and future psychosocial outcomes, as all SA face to face activity was suspended from March 2020. Nevertheless, this unprecedented situation provided opportunity for us to explore i) how SA groups continued and maintained contact with stroke survivors during the pandemic and, ii) how group members' experiences of their stroke group during the pandemic related to their wellbeing.

Methods

Survey

Surveys were distributed and completed on average around 3-months after the start of the first UK lockdown, between 16th June and 4th July 2020. Where permissions were in place, SA group members and volunteers were emailed an invite to complete this survey which could be completed online or over the telephone. All items were presented in an 'aphasia-friendly' manner. Paper-based surveys were not used due to concerns about asking those in lockdown/shielding to post these back.

Participants completed the same demographic and psychosocial outcomes as per the first survey (See Table 1) as well as some pandemic specific ones:

- Respondents' 'shielding' status was captured by asking 'Have you or any of your household been sent a letter from the NHS to say you should be shielding during the COVID-19 pandemic?' (No/Not Sure, Yes);
- Frequency of contact ('Thinking about your contact with other stroke group members, how often have you kept in contact during the COVID-19 pandemic...'), and type of contact by/using nine different formats (e.g. phone calls, emails and texting people individually, reported on a 6-point scale - not at all, less than once a month, once a month, once a fortnight, once a week, multiple times a week) with their stroke groups during the pandemic.

Researchers calculated the number of days spent in pandemic restrictions at the point of survey completion. Finally, a number of open-ended questions relating to stroke group contact and support during the pandemic restrictions were included: 'How else have your stroke group kept in contact during the COVID-19 pandemic?', 'In what way has your stroke group supported each other during the COVID-19 pandemic?' and 'Could your stroke group be doing more to support each other during the COVID-19 pandemic?' (response option Yes or No), followed by 'Name one thing your stroke group could do to support each other better during the COVID-19 pandemic?' for those who responded 'yes'.

Telephone interviews

A selection of group members and volunteers who participated in the pandemic survey were invited to a telephone interview between January and March 2021. Invitations were strategic to better understand the experiences of as varied a sample as possible. Group members were invited based on: age variation (>80, 65< and ≥80, and ≤ 65); gender (male/female); group type (activity-based, support/social group/café or speakability); and responses to the earlier survey (high and low loneliness, social identity, and perceived social support from the group). Volunteers were invited based on varied age and gender, and to represent a number of group types. Some of the volunteers had taken part in the pandemic survey as stroke survivors, other volunteers had not had a stroke. Verbal consent was received at the outset of the interviews which were completed over the phone or using Zoom. Interviews were audio-recorded, transcribed and anonymised. Pre-set questions were used as a basis to structure the interview. Questions were asked flexibly as part of a guided conversation, asking participants about their experiences of the stroke group before and during the pandemic.

Data Analyses

Survey

Survey responses were treated in the same manner as for the pre-pandemic survey. Descriptive data were summarised using means and percentages where relevant. Separate univariate multilevel regression models were run to assess the relationship between the demographic measures and group identification on loneliness and wellbeing. Again, due to the exploratory nature of this research, many comparisons were made; results were not corrected for multiple comparisons, and findings should be interpreted in light of this.

Qualitative responses (open-ended survey items & telephone interviews)

Open-ended responses from the pandemic survey were analysed using a qualitative description approach⁴⁵. This approach is inductive and so describes the dataset rather than testing pre-established theory. Trained researchers (RL and LH) coded the full data independently in NVivo 12 using thematic analysis⁴⁶. The themes resulting from these independent analyses were compared and notable discrepancies discussed to ensure all relevant themes were included in the final thematic groupings.

Telephone interviews were coded using a qualitative description approach, and analyses were supported by Nvivo software. The primary coder read the interview transcripts in full prior to coding for familiarity and then repeated this exercise again, but this time coding to identify meaningful units of text relevant to the research questions. Units of text covering similar themes were grouped together under the same code and groups were given names and definitions. The same unit of text could be included in more than one group. Once all transcripts were fully coded, the categories and the text assigned to them were reviewed to ensure each was suitably supported by examples. Within this process, a second coder coded the first 8 transcripts, and a consensus

meeting was held to discuss similarities and discrepancies. All existing codes were then reviewed in-light of these discussions and all further transcripts coded in accordance with this.

Results

Survey

A total of 260 responses were obtained (250 online; 10 telephone) from 118 different stroke groups across the United Kingdom (M = 2.2 responses per group; SD = 1.6; range 1–8). Participant characteristics are described in Table 3a and group activity type and group meeting frequency are shown in Table 3b. As indicated in Table 3a, levels of loneliness, wellbeing and social identity were comparable to those observed during the pre-pandemic survey.

Table 3a Participant characteristics (pandemic)	
Respondent characteristics	
Number of respondents (n)	260
Age at T2 (years), mean (SD)	66.5 (10.4)
Gender, n (% female)	112 (43.1)
Role in the group, n (% volunteer)	90 (34.6)
Questionnaire version completed (% simplified survey)	N/A
Living arrangements, n (%)	
On my own	60 (23.1)
With family	168 (64.6)
With non-family	5 (1.9)
Residential / nursing home	1 (0.4)
Other	23 (8.9)
Time since stroke, n (%)	
<1 year	5 (2.0)
1-2 years	41 (15.8)
3-5 years	70 (26.9)
6-10 years	68 (26.2)
>10 years	58 (22.3)
Overall health, n (%)	
Poor	16 (6.2)
Fair	96 (36.9)
Good	120 (46.2)
Excellent	18 (6.9)
Received a "shielding" letter, n (%)	
No	195 (75.0)
I have	37 (14.2)
Someone else in household	17 (6.5)
Both I and someone else	1 (0.4)
Not sure	4 (1.5)
Days since the start of pandemic restrictions, mean (SD)	88.7 (5.7)
Measures	
Loneliness, M (SD)	5.2 (1.9)
Are lonely, n (%)	108 (43.72)
Wellbeing, M (SD)	22.0 (3.9)
Group identification, M (SD)	3 (0.9)
Perceived social support, M (SD)	49.1 (23.9)

Percentages will not always equal 100 due to missing data

Table 3b Group characteristics (pandemic)

Group characteristics	
Number of groups represented (N)	118; Participants N= 260
Group location, n (%)	
C1-C2	83 (31.9)
N Ireland	19 (7.3)
N1-N4	48 (18.5)
S1-S3	73 (28.1)
Scotland	15 (5.7)
Wales	14 (5.4)
Missing	8 (3.1)
How often the groups meet, n (%)	
Weekly	116 (44.6)
Fortnightly	69 (26.5)
Monthly	62 (23.8)
Other	1 (0.4)
Missing	12 (4.6)
Group description, n (%)	
Social Support	176 (67.7)
Speakability / Aphasia	41 (15.8)
Exercise	2 (0.8)
Singing	4 (1.5)
Creative Arts	13 (5.0)
Stroke Cafe	15 (5.8)
Other	1 (0.4)
Missing	8 (3.1)

The role of group processes on psychosocial outcomes

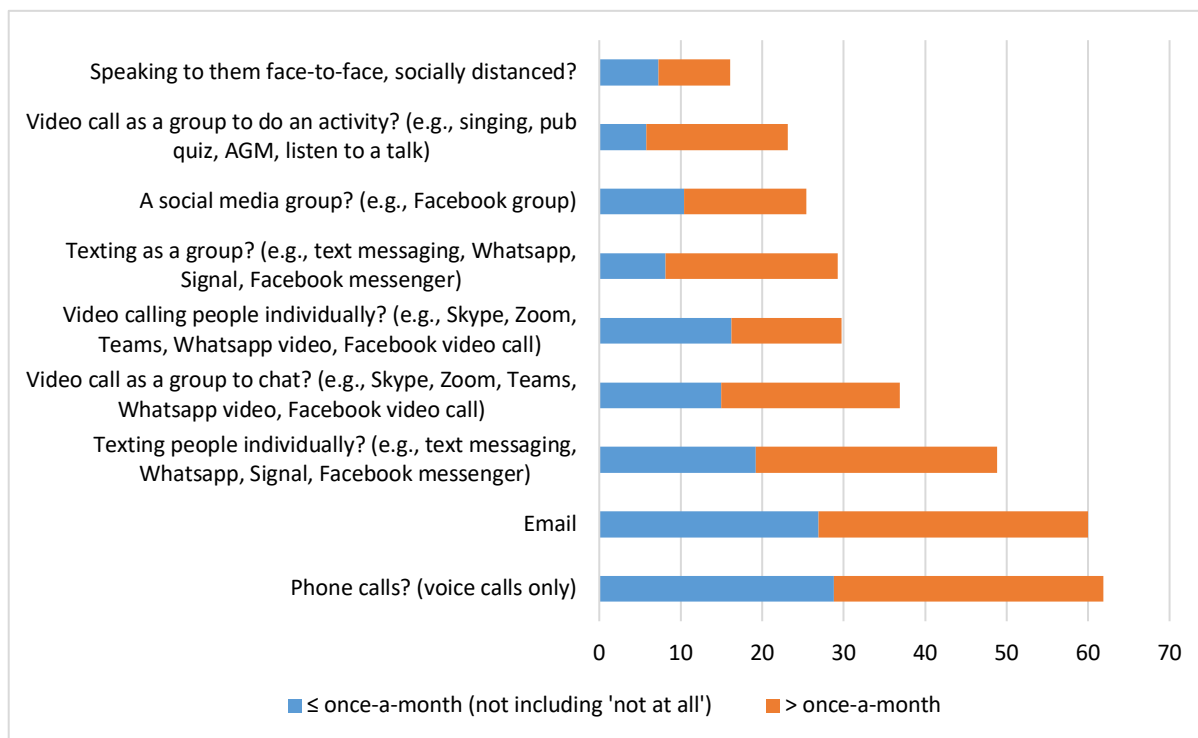
Wellbeing: Being a volunteer rather than a group member and having perceived good to excellent health were associated with higher wellbeing. Shorter length of membership of a peer-support group was also related to higher wellbeing. However this effect was weak and we therefore recommend that it be interpreted with caution (see appendix E).

Loneliness: Strongly identifying as a group member and feeling supported were significantly associated with lower levels of loneliness. Individual circumstances, such as living on their own, perceiving poorer personal health and being a group member as opposed to a volunteer were all associated with higher levels of loneliness. There was also an association between longer length of group membership and loneliness (see appendix E). Again this finding was weak.

Maintenance of contact during the pandemic

Three months after the suspension of in-person group meetings, 87% of stroke group members/volunteers had maintained some contact with their stroke group. Shown in more detail in Figure 1, this contact predominantly comprised speaking over the telephone (62%), emails (60%), and text-based messaging with other members/volunteers from their group (49%). Each mode of contact is further split by how frequently it was used, either less than once-a-month or more than once a month

Figure 1. Percentage of respondents using each type of contact during the pandemic



Interviewee characteristics

Twelve group members (two of which had their partners present), and eight volunteers took part in telephone interviews (see appendix F). All were stroke survivors apart from the two partners and two of the volunteers. Of the group members five interviewees were female and seven male. Five participants were aged 65 and under, four between 65 and 80 and three over 80. The volunteers comprised two males and five females. Three volunteer participants were aged under 65, with two over 65. For two participants age was not recorded. Passive group types (n=4) were the most commonly volunteered (support social groups/ café's) with two volunteers supporting Active groups (activity of group therapy) and one volunteering at an aphasia group.

Key findings emerging from both the telephone interviews and the open-ended responses are presented here (all quotes are from the interviews unless otherwise specified).

Role of group processes

Telephone interviews reflected the importance of group processes both from before and during the pandemic. There was strong evidence that, for many respondents, shared experience and understanding from within the group was central to their positive experience of the group:

"It's just a catch up really. It's nice just to have that connection with those people. You might not necessarily be talking about strokes.... It's like a group of people who get you.... It's just really supportive because everybody kind of is in the same boat even if you are affected in different ways." [member]

"there's some quite nice friendships that I've built up over time...And then other people, not necessarily friendships but have quite... you know, I've got a good positive relationship with everybody really." [member]

Respondents also talked about how stroke groups provided a way to make contact with others or re-connect with the world after stroke. This need for contact and communication persisted during the lockdown and when groups moved onto Zoom:

“That’s all people need is communication and a bit of empathy. That’s all. That’s all in life. That’s all people need. Because, ‘I don’t know if you’re alright. Okay, I need to talk to you,’ and they don’t feel isolated.” [volunteer]

“Most of us need some sort of human contact, and the Zoom meetings are a great media for it” [volunteer]

“Oh, just go. It’s amazing. It’s a way to get your life back on track, I would say. Because what they do is they teach you to kind of let go of your old self and kind of embrace the new you. And that’s something that you can’t do on your own.” [member]

“...you saw people who’d had a stroke 10 years ago and were still there and getting on with life.” [member]

“Well I suppose when I first went I was very aware that there were a lot of people much more affected by stroke than I was.... I think it was encouraging, in a way, that I was less worried by stroke than some, which might sound rather selfish, but...” [member]

Not only were the groups a place for sharing experiences, participation in them also provided meaningful learning opportunities. This opportunity to learn different ways to do things was not limited to the stroke survivors. Some of the groups had carers join or stay for some of the time, or even connect outside the group. These instances indicate how the group may have wider benefits.

“You also pick-up bits of information on how people cope with certain things. You know, you maybe find something which you can’t really do yourself, and they go, ‘Oh yeah, if you do this, this and this,’ or, ‘If you get this particular thing you’ll find it makes life a lot easier.’ Yeah, this is what it’s all about.” [member]

“Well, we’ve been quite fortunate, I mean not so much [participant’s name], bless him, but for the wives, when we drop them off, Speakability, we all used to go for coffee so we’d made quite a nice support group.” [partner of member]

“They have someone from the Carers’ Association comes in, sort of, I think once a month - it seems a long time ago now to remember now...How it all works - and that’s been really helpful for my family...To be able to sort of get some information from that point of view, so I think that’s what... yeah...” [member]

In summary, the groups can be seen as providing a space that enables members to be defined not just by their disability, but also as a place to find some kind of acceptance for who they are as an individual. They could see that for members at the group, having a stroke was not a barrier to getting on with their lives and some members gained a more balanced perspective on their circumstances, with some people affected to a greater or lesser extent than others.

Impact of the pandemic on engagement

The majority of respondents thought their stroke group had provided adequate support during the pandemic, with comments about virtual groups being on the whole positive. Attempts to contact were generally well appreciated:

“...people who can’t get to the groups can get to Zoom meetings. I think they’re invaluable...” and *“Most of us need some sort of human contact, and the Zoom meetings are a great media for it and I have received 1 call from [name redacted] who co-ordinates the stroke meeting I attend. She was just checking I was keeping ok and she had been calling other group members. Very appreciated.”* [member – open ended survey response].

“[name redacted] the secretary has phoned to see if we are ok and has given us news about other members of the group. She phones about every 2 weeks.” [member, open ended survey response]

“We have a monthly newsletter sent out by email which is a nice way to keep in touch with the group.” [member, open ended survey response]

However, some participants thought their stroke group could have done more in terms of support with one participant stating *“I think there could have been more contact”* and another participant feeling that contact should have been more frequent *“The way it was set up, it was only once a month...But for me it would have been better if it was just once a week or once a fortnight rather than once a month. It’s a long time at times”*

Stroke groups varied in frequency of virtual meetings with some meeting more than once a week and others once a month. Groups tended to try and engage members at meetings running activities such as quizzes, bingo and one group asked members to bring paintings to the sessions for group discussion. Other groups met to have a chat with each other but may also have comprised some activity such as a quiz alongside the discussion element.

There were some challenges of meeting virtually. Despite having the requisite technology for virtual/remote contact, some respondents were not able to maintain, or had minimal contact with their group. Reasons for this varied and some participants were unaware of contact opportunities *“...I’ve never gone to any so whether or not they just don’t bother anymore or they’ve... they’re not having them, you know don’t have them.”* Other reasons for not engaging with their stroke group included issues operating the technology (i.e. mobile phones, laptops, programmes such as Zoom). Reasons for not being able to operate the technology may have been as a result of stroke related disability *“...I would have liked perhaps... because I can’t do Zoom. You know, even if it was only every couple of months, maybe a phone call.”* [member], or unfamiliarity on the part of both the stroke survivor and any relatives or carers. Where stroke-related disability posed an issue with connectivity some groups were able to contact members in other ways *“We’ve had a couple of emails asking if we’re okay, and a telephone call.”* [group member’s wife]

A related issue was needing help from friends, family or carers to facilitate their contact with the group, and the availability of these individuals at the time the group was meeting was not always possible. For members where connectivity or issues using Zoom were known, some session leaders and volunteers checked how the group member was *“Well [group leader name]...he’s a co-ordinator. He’ll phone them to see if they’re alright...every week”* [volunteer] whilst other groups decided that running online groups was not feasible so used other ways to maintain contact with their members *“...we divided up the members into then four/five groups and said, well, we’ll give you a call and we’ve kept doing that all the way through, so once-a-month or so...”* [volunteer]. Finally, issues pertaining to how well the person felt they knew the group affected how well members maintained contact during the pandemic, as did how close they felt with other members prior to the pandemic.

Stroke groups on the whole were adaptive to the pandemic and did what they could to continue supporting their members. Group members were appreciative of the efforts that the leaders and volunteers went to implementing ways in which groups could still meet to receive the benefits obtained through being a member of a stroke group. For many, having contact during the pandemic was a way to *“Just to know we are feeling the same in lockdown”* [volunteer].

Discussion

The SA peer-support groups are highly valued by stroke survivors who participate in them and findings from both the surveys and the individual interviews we conducted for this project highlight the clear impact that the groups can have on psychosocial health. These findings add to the earlier research for the SA that indicated some of the broad benefits of participation in the peer-support groups⁴⁷. The ill-health consequences of stroke, both in terms of physical impairments and also effects on wellbeing and general psychosocial health are well-documented⁷⁻¹¹; and the Stroke Association and James Lind Alliance Priority Setting Partnership have identified psychological problems caused by stroke as a priority area⁴⁸ – although uncertainties remain about how best to attend to these hidden impacts of a stroke⁴⁸. However, on the basis of the findings from the current research, it can be suggested that the SA peer-support programme is well-placed to help in this regard. Indeed, the high levels of attendance at the groups we studied, and length of membership, is testament to the strong appetite amongst stroke survivors for this form of support.

The current project uniquely illustrates the role that stroke survivors' sense of social identity derived from the peer-support groups plays in shaping any health benefits of participation. Indeed, members' identification with the peer-support group was found to be associated with levels of loneliness and wellbeing. That is, to the extent that group members had formed a strong sense social identity within the group, they expressed lower levels of loneliness and higher wellbeing. . This pattern was most pronounced in the pre-pandemic survey, when groups were meeting face-to-face, but there was also evidence for it, particularly in terms of the relationship with loneliness, in the pandemic survey as well when groups could not meet face-to-face.

These findings are in keeping with the social identity approach to health ^{19 20}, outlined earlier, and confirm that the peer-support groups here may have served as a valuable resource that group members were able to draw upon. This resource was manifested in the current research in terms of increased social support, social connectedness, and self-efficacy (agency) amongst group members who highly identified with their group.

One of the original objectives for this project was to document changes in health and group experiences amongst stroke survivors across the course of a calendar year. As was the case with much health research at the time, the Covid-19 pandemic presented a major disruption to our project. Principally, with the peer-support groups no longer meeting in-person, we were unable to conduct the second survey as planned. However, the pandemic presented us with an opportunity to explore an important question: whether the peer-support groups served as a valuable resource for stroke survivors even in the absence of face-to-face meetings.

Overall, a resilient and adaptive response to the pandemic by the peer-support groups was observed. Some 87% of group members reported having contact with their groups within three months of the pausing of in-person meetings, with the main contact methods being telephone calls, emails and text-based messaging. These adaptations provided an opportunity for group members to (re-)interact with other members, and thereby sustain their sense of connection to the group. Indeed, it is notable that the strength of social identification with the group as measured during the pandemic, when groups could not meet in-person, was largely indifferent from that measured in the pre-pandemic survey, when groups were meeting regularly in-person.

The qualitative findings in particular illuminated the value of being a member of a peer-support group. Participants talked about how their shared experience and understanding from the groups was key to their positive experience of the group. The value that respondents attributed to their group was especially marked during the pandemic when face-to-face interaction (with anyone outside of the immediate family) was substantially curtailed. During the pandemic, a large number

of groups moved meetings onto virtual platforms such as Zoom which enabled those who could access these systems to still meet with one another, as group members did not seem to contact one another during the pandemic outside of the groups. Meetings on the platforms varied in terms of frequency and ranged in terms of group focus. Despite this variation in meeting frequency and topic- and method of contact for those that did not/ could not make the Zoom calls, such as volunteers phoning members directly – some individuals felt that more could have been done to support them. This said, 57% of respondents felt adequately supported during the pandemic.

Group leaders went to considerable efforts to provide these opportunities for their groups to meaningfully interact, with some introducing virtual quizzes, bingo and other social activities that may have contributed to the positive outcomes reported. From the perspective of the social identity approach introduced earlier, these group leaders can be seen as engaging in a process of *social identity leadership*⁴⁹. That is, the group leaders took actions which helped to nurture and reinforce the sense of ‘we and us’ amongst the group members by providing opportunities for them to come together and reconnect *as a group*. Some of our other recent research has formalised actions that group facilitators can follow in order build shared social identity in group programmes²²; and these actions emphasise the importance of continuous monitoring of the group in order to optimise members’ opportunities to connect.

A clear pattern that emerged across this project, then, is the formation of a strong social identity as a member of the peer-support group which is fundamentally linked to the health effects of group participation, especially in face-to-face settings. However, a remaining question concerns the factors that may contribute to the emergence of a social identity. That is, how do people come to identify with the group? The findings here indicated that both structural factors and the psychological readiness of stroke survivors to engage with a group contribute to this process. While many of these variables are clearly not modifiable (e.g., sense of self as a stroke survivor) other variables pertain to the organisation of the groups and potentially could be modified (e.g., by encouraging groups to meeting no less than weekly, supporting regular attendance).

Structurally, having the same people attend the group each week (‘group continuity’), meeting no less than once per week, and being a member for longer were factors found to be associated with social identification. Meeting frequently as a group ensures that the group becomes psychologically salient for the members – meaning that the social identity becomes something that group members can readily draw upon to define the self. Having the same people attend the group each week likely enables members to become more familiar with each other than they otherwise could, thereby building trust and related processes that are characteristic of strong social connectedness. Although social identification has been shown in some of our other research with stroke survivors (specifically people with aphasia after a stroke) to increase early in a group programme and then somewhat stabilise over time⁵⁰, the finding here that group membership is associated with strength of social identity indicates that, at least in these peer-support groups, social identity may be something that continues to evolve over time – and this may signal the importance of an ongoing monitoring of the group by the group leader as suggested above

In terms of psychological readiness to identify with the group, the findings indicated that seeing oneself as a stroke survivor and also belonging to many *other* social groups were both positively associated with social identification. Seeing oneself as a stroke survivor may increase perceptions that the group is a good ‘fit’ for oneself, or “something for me”. Stroke is stereotypically regarded as something that is experienced by ‘older people’. Therefore it is possible younger stroke survivors may feel less likely to consider that they fitted in with groups – and perhaps would be less ready to self-define *in terms of* their stroke. The finding that multiple group membership was associated with social identification is consistent with previous research⁵¹ and may indicate that participation in

multiple social groups confers a cumulative experience that instils confidence in members and enables them to effectively utilise the groups as a psychological resource in support of their ongoing rehabilitation.

Study limitations

It should be noted that participants in this research were individuals who had chosen to engage with the SA peer-support groups, and who had chosen to take part in the research. Consequently, the findings from the research are limited to this sub-population of stroke survivors and cannot be generalised to those who, for whatever reason, had chosen not to join a SA group or chose not to take part in the research. Some research has begun the process of trying to identify and talk to people who choose not to join social groups and to understand the reasons for this⁵². Such research has identified several barriers to participation, including shyness, a sense of inadequacy in groups, and physical (health) or personal barriers. Some of these barriers were apparent in the current research: as noted above, some of the younger stroke survivors we interviewed reporting that they did not feel that they fitted in well with the group.

Despite the large sample and wide reach of the pandemic survey (260 stroke survivors from 118 groups across the United Kingdom), the self-selecting nature of the sample and the predominant use of the online delivery format for completion (as opposed to the telephone) may have biased this sample towards stroke survivors who have access and use of the internet. These individuals may be more adept at maintaining (or initiating) contact with others when in-person group meetings were not possible. We therefore caution that the patterns reported here may not generalise to other stroke survivors.

The various other possible social groups that people identified with and received support from during the pandemic were not assessed here. Other group memberships and sources of support may have become more important resources for participants during this time when SA groups could not meet in-person. Future research should consider the potential impacts of these wider, multiple, group memberships on stroke survivors' health and wellbeing. Finally, while the overall pattern of findings confirm the potential beneficial impact of the SA peer-support groups on loneliness and wellbeing, it should be remembered that groups such as these may not be suited to all stroke survivors – and potentially could even be detrimental to health and wellbeing if people are unable, or do not wish, to integrate into a group⁵². The inability to integrate into a group may be a particular challenge for new members, who come to groups such as these with pre-existing identities that may be incompatible with one of being a stroke group member⁵³, and highlights the importance of attending to people's early experiences and 'first impressions' of the group²².

Conclusion

This project documents stroke survivors' experiences of the SA's peer-support group programme, with a specific focus on psychosocial health. The research covered the period prior to the Covid-19 pandemic, when the peer-support groups were meeting in-person, and during the pandemic when in-person meetings had ceased.

Stroke survivors clearly valued their membership of the peer-support groups. This was evidenced both in the quantitative surveys, where high levels of engagement with the groups was observed, and in the qualitative interviews, where respondents described in their own words how they benefited from their membership. When measured prior to the Covid-19 pandemic, levels of loneliness amongst survey respondents were higher than has been previously observed in *non-*

stroke survivors from the general population. Wellbeing levels were broadly comparable to the general population at this time. Notably, participants' experiences of the groups when they were meeting face-to-face, in terms of their social identity and related group processes, were associated with better psychosocial health. Despite the cessation of in-person group meetings, there was a clear pattern of resilience amongst the groups we studied, with a move by many to online meetings. Participants talked about how much they valued being able to maintain contact with their group and it seems possible that these experiences contributed to the apparent consistency in wellbeing and loneliness levels during the pandemic (compared to pre-pandemic levels).

Finally, the project has illuminated factors that may predispose stroke survivors to engage well with the peer-support groups, in particular in terms of 'who' is most likely to develop a strong sense of social identity as a member of the group – and when they might do this. In this regard, the current project signals several factors that may benefit from targeted intervention, both at a structural, organisation level prior to group set-up, and in terms of managing group members' experiences of the group once they have joined it.

Key Messages

- This national survey documented stroke survivors' experiences of the Stroke Association peer-support groups prior to and during the early stages of the COVID-19 pandemic.
- Stroke survivors who participated in this study reported higher levels of loneliness than the general population but broadly similar levels of wellbeing. Notably, these levels appeared to be consistent between the pre-pandemic and pandemic surveys.
- Participation in a peer-support group appeared to enable stroke survivors to manage their psychosocial health. Specifically, we saw that members' sense of social identity as a group member was associated with experiencing the group as a resource for social support, a sense of group connection, and these experiences were also associated with their psychosocial health (specifically, loneliness).
- The findings indicated that more frequent contact with a peer-support group (i.e., about once a week), regular attendance at group meetings, and having contact with broadly the same individuals each time was important. Supporting groups to meet frequently and encouraging members to attend as many sessions as possible may help provide a stable environment and sense of group continuity amongst the members, and in turn enable stroke survivors to better manage their psychosocial health.
- While some factors impacting individuals' readiness to engage with a peer-support group cannot be modified (e.g., seeing oneself as a stroke survivor), structurally it may be possible to organise the groups in a way which makes it easier for group members to develop a shared social identity, as noted above. Additionally, facilitators should be alert to the possible (negative) impact of new members on the existing group atmosphere and consider how to effectively integrate these within the group. One suggestion might be to pair up new members initially with established, well-networked members (so-called 'connectors') within the group.
- Data from both the survey and interviews suggested that groups were adaptive/reflexive to the suspension of face-to-face meetings. Although contact with group members during the pandemic was well received, the contact primarily involved telephone calls from a group leader on a one-to-one basis. Going forward, the Stroke Association may wish to extend and formalise contingency plans that were developed *in response* to the pandemic so that group leaders across the network can ensure maintenance of contact *between members* during periods that are understandably disruptive for the individuals concerned.

Project outputs

Conference seminar presentations:

International Conference on Social Identity and Health 'Taster Event', Nottingham (2021). *"If you build it they will come". Applying the social identity model of behavior change in community and clinical interventions.*

International Conference on Social Identity and Health 'Taster Event', Nottingham (2021). *"Social Identity and loneliness: Results from a national cross-sectional survey of peer support groups for stroke".*

Nottingham Trent University, School of Psychology (2020). *"If you build it they will come". Applying the social identity model of behavior change in community and clinical interventions.*

Published articles:

Lamont, R. A., Calitri, R., Mounce, L. T. A., Hollands, L., Dean, S. G., Code, C., Sanders, A., & Tarrant, M. (2022). Shared social identity and perceived social support among stroke groups during the COVID-19 pandemic: Relationship with psychosocial health. *Applied Psychology: Health and Well-Being*. <https://doi.org/10.1111/aphw.12348>

We are currently preparing other aspects of the project for publication.

About this report

The project

This research project was formally known as the 'Community Groups for Post-Stroke Support' study at the University of Exeter, UK (Twitter: [@CoGS_study](#)).



The CoGS study was funded from the National Lottery Community Fund (previously Big Lottery), in partnership with Nesta, as part of their support for the Stroke Association's expanding peer support network.

Ethical approval for the study was granted by the University of Exeter College of Medicine and Health Research Ethics Committee (ref: Oct19/B/223).

Contributors

All researchers are based at the University of Exeter. The study was led by Associate Professor Mark Tarrant (principal investigator), Dr Ruth Lamont (project manager), and Dr Raff Calitri (co-investigator), supported by: Laura Hollands (PhD researcher), Dr Luke Mounce (co-investigator), Professor Sarah Dean (co-investigator), Professor Chris Code (co-investigator), Dr Jess Bollen (researcher) and Dr Amy Sanders (co-investigator).

The project was supported by an advisory group of individuals with experience of stroke and leading a peer-support group themselves. The advisory group contributed to both reviewing the survey and interview designs, and advising on contact with stroke groups. They continue to support the project as it is written-up and shared with others.

With thanks to

The authors express their gratitude to the many individuals that took part in this research. This research would not have been possible without them. We would also like to thank our advisory group of people with experience of stroke for their support with the development of this work. We are also hugely grateful to Beth Scrimshaw and Jane Tooke at the Stroke Association for their enthusiasm and guidance throughout.

Sarah Dean's and Mark Tarrant's time is partly supported by the National Institute for Health and Care Research Applied Research Collaboration South West Peninsula. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care, UK.

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Appendices

Appendix A: Correlations between all group process predictors (variables).

Predictor	Group identity	Social support	Group autonomy
Group identity	1		
Social support	.57	1	
Group autonomy	.35	.40	1
Connection	.62	.60	.51

Appendix B: Association of loneliness with group identity, social support, and connection

B-coefficients and 95% confidence intervals from multiple regressions of the relationships between group identity, group processes, other covariates, and **loneliness**

Predictor	Group identity	Group autonomy	Social Support	Connection
B (95% CI)	-0.46** (-0.77 – -0.14)	-0.41 (-0.92 – -0.09)	-0.02*** (-0.03 – -0.01)	-0.45* (-0.87 – -0.03)
β (95% CI)	-0.28** (-0.48 – -0.09)	-0.18 (-0.39 – 0.04)	-0.42*** (-0.62 – -0.23)	-0.45* (-0.87 – -0.03)
Covariates B (95% CI)				
Age (years)	-0.03** (-0.04 – -0.01)	-0.03** (-0.05 – -0.01)	-0.03** (-0.05 – -0.01)	-0.03** (-0.05 – -0.01)
Live alone	0.52* (0.09 – 0.95)	0.51* (-0.07 – 0.95)	0.52* (0.09 – 0.95)	0.56* (0.12 – 0.99)
Perceived health				
Poor/Fair	Ref	Ref	Ref	Ref
Good/Excellent	-0.91*** (-1.31 – -0.52)	-0.95*** (-1.35 – -0.55)	-0.88*** (-1.27 – -0.49)	-0.94*** (-1.33 – -0.54)
Time since stroke (years)				
0 – 2	Ref	Ref	Ref	Ref
3 – 5	-0.40 (-1.01 – 0.20)	-0.38 (-0.99 – 0.23)	-0.41 (-1.00 – 0.19)	-0.38 (-0.99 – 0.23)
6 – 10	-0.39 (-1.05 – 0.27)	-0.36 (-1.02 – 0.31)	-0.47 (-1.13 – 0.18)	-0.39 (-1.06 – 0.27)
> 10	-0.66* (-1.32 – -0.002)	-0.70* (-1.37 – -0.04)	-0.74* (-1.39 – -0.09)	-0.72* (-1.38 – -0.06)
Volunteer	-0.31 (-0.81 – -0.19)	-0.17 (-0.68 – 0.34)	-0.25 (-0.74 – 0.24)	-0.28 (-0.78 – 0.23)
Length of time in group				
< 12 months	Ref	Ref	Ref	Ref
>= 12 months	0.30 (-0.27 – 0.87)	0.17 (-0.39 – 0.74)	0.33 (-0.23 – 0.90)	0.22 (-0.35 – 0.79)

Appendix C: Association of wellbeing with group identity, connection, social support and autonomy

B-coefficients and 95% confidence intervals from multiple regressions of the relationships between group identity, group processes, other covariates, and wellbeing				
Predictor	Group identity	Group autonomy	Social Support	Connection
predictor, B (95% CI)	1.52*** (0.80 – 2.23)	1.19* (0.10 – 2.28)	0.05*** (0.03 – 0.07)	1.44** (0.50 – 2.39)
predictor, β (95% CI)	0.94*** (0.49 – 1.39)	0.51* (0.04 – 0.98)	1.11*** (0.67 – 1.55)	0.69** (0.24 – 1.14)
Covariates B (95% CI)				
Time since stroke (years)				
0 – 2	Ref	Ref	Ref	Ref
3 – 5	1.32 (-0.02 – 2.67)	1.28 (-0.08 – 2.64)	1.32* (-0.0003 – 2.65)	1.23 (-0.13 – 2.58)
6 – 10	1.15 (-0.32 – 2.61)	0.21 (-0.28 – 2.69)	1.41 (-0.03 – 2.85)	1.25 (-0.23 – 2.72)
> 10	2.27** (0.77 – 3.76)	2.43** (0.93 – 3.94)	2.57** (1.10 – 4.03)	2.48** (0.99 – 3.98)
Perceived health				
Poor/Fair	Ref	Ref	Ref	Ref
Good/Excellent	3.61*** (2.73 – 4.49)	3.67*** (2.78 – 4.56)	3.51*** (2.64 – 4.39)	3.67*** (2.78 – 4.56)
Volunteer	0.66 (-0.47 – 1.79)	0.31 (-0.83 – 1.44)	0.41 (-0.69 – 1.51)	0.59 (-0.54 – 1.72)
Length of time in group				
< 12 months	Ref	Ref	Ref	Ref
\geq 12 months	-1.11 (-2.41 – 1.79)	-0.77 (-2.07 – 0.53)	-1.10 (-2.38 – 0.18)	-0.90 (-2.20 – 0.40)
Frequency attendance				
Less than nearly every session	Ref 0.44 (-0.63 – 1.52)	Ref 0.60 (-0.49 – 1.69)	Ref 0.40 (-0.67 – 1.47)	Ref 0.45 (-0.64 – 1.54)
Every, or nearly every session				

Association between psychological factors, structural factors and group identification

Appendix D: Factors affecting Group identification

Predictor	Univariate models		
	B Co-efficient	95% CI	P-value
Identity centrality	0.14	0.03 – 0.26	0.016
Pre-stroke group memberships	0.01	-0.09 – 0.11	0.839
Post stroke group memberships	0.18	0.07 – 0.29	0.002
Know other members	0.10	-0.01 – 0.22	0.071
Group continuity	0.36	0.26 – 0.46	>0.001
Frequency group meeting			
Weekly	ref	ref	ref
Fortnightly	-0.26	-0.41 - -0.10	0.001
Monthly	-0.18	-0.34 - -0.03	0.022
Other	0.08	-0.29 – 0.45	0.675

Appendix E: Estimated effects of perceived social support and group identification on loneliness and well-being, univariate analyses (pandemic survey).

	Wellbeing		Loneliness	
	Coefficient (95% CI)	p-value	Coefficient (95% CI)	p-value
High group identification	0.69 (-0.25 to 1.64)	0.151	-0.62 (-1.15 to -0.1)	0.020
Social support	0.01 (-0.01 to 0.04)	0.242	-0.01 (-0.02 to 0.00)	0.053
Age (years) at T2	0.01 (-0.03 to 0.05)	0.711	0.00 (-0.03 to 0.02)	0.885
Female gender	-0.32 (-1.26 to 0.63)	0.514	-0.35 (-0.90 to 0.20)	0.209
Days in lockdown	0.01 (-0.09 to 0.11)	0.843	0.01 (-0.05 to 0.06)	0.807
Lives alone	0.27 (-0.72 to 1.26)	0.592	0.77 (0.12 to 1.42)	0.020
Time since stroke				
0-2 years	Reference group	n/a	Reference group	n/a
3-5 years	-0.01 (-1.41 to 1.40)	0.994	-0.40 (-1.11 to 0.31)	0.265
6-10 years	-0.17 (-1.46 to 1.11)	0.793	-0.22 (-0.98 to 0.54)	0.576
>10 years	0.78 (-0.68 to 2.24)	0.294	-0.33 (-1.07 to 0.40)	0.377
Overall health				
Poor/fair	Reference group	n/a	Reference group	n/a
Good/excellent	3.55 (2.62 to 4.47)	<0.001	-1.28 (-1.92 to -0.64)	<0.001
Received "shielding" letter				
No	Reference group	n/a	Reference group	n/a
≥1 in household	-0.79 (-1.88 to 0.31)	0.158	-0.23 (-0.94 to 0.48)	0.523
Role in group				
Volunteer	Reference group	n/a	Reference group	n/a
Member	-1.11 (-2.14 to -0.09)	0.034	0.75 (0.16 to 1.33)	0.013
Other	-0.47 (-1.33 to 0.39)	0.283	Excluded ¹	n/a
Length of group membership				
<12 months	Reference group	n/a	Reference group	n/a
≥12 months	-1.29 (-2.73 to 0.14)	0.078	0.71 (-0.05 to 1.46)	0.066

¹"Other" role in group was excluded from this model due to issues of multicollinearity.

Appendix F: Sample descriptives for telephone interview participants- group members

Gender	Age	TOTAL	Group identification		Perceived social support		Loneliness		Group type		
			<i>Below the mean</i>	<i>Above the mean</i>	<i>Below the mean</i>	<i>Above the mean</i>	<i>Below the mean</i>	<i>Above the mean</i>	<i>Active (activity or therapy group)</i>	<i>Passive (support/social group/cafe)</i>	<i>Aphasia (speakability)</i>
Female	>80	1	1	0	1	0	1	0	0	1	0
	65< and ≥80	2	1	1	1	1	1	1	1	1	0
	≤ 65	2	2	0	0	2	1	1	0	2	0
Male	>80	2	1	1	1	1	1	1	1	0	1
	65< and ≥80	2	0	2	0	2	1	1	1	1	0
	≤ 65	3	1	2	1	2	2	1	0	2	1

Sample descriptives for telephone interview participants- group volunteers

Gender	Age	TOTAL	Group type		
			<i>Active (activity or therapy group)</i>	<i>Passive (support/social group/cafe)</i>	<i>Aphasia (speakability)</i>
Female	≤ 65	1	1	0	0
	> 65	2	1	1	0
	unknown	2	0	1	1
Male	≤ 65	1	0	1	0
	> 65	1	0	1	0