

Shared social identity and perceived social support among stroke groups during the COVID-19 pandemic: Relationship with psychosocial health

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Abstract

Community-based peer support groups for stroke survivors are common in the United Kingdom and aim to support rehabilitation. This study of 260 stroke survivors across 118 groups nationally used an online survey format, completed on average 3 months into the pandemic. Analysis of both quantitative and open-ended responses provided insights into how stroke group members maintained contact during the COVID-19 pandemic and how the group processes of shared social identity and perceived social support related to psychosocial outcomes (self-esteem, well-being and loneliness). Group members adapted to the pandemic early through telephone calls (61.6% of participants) and internet-based contact (>70% of participants), although also showed a desire for greater contact with their groups. A stronger sense of shared social identity and perceptions of social support from the stroke groups were weakly associated with reductions in loneliness among members, and greater

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perceived social support was associated with higher self-esteem. However, having poor health and living alone were more strongly associated with more negative psychosocial outcomes. The discussion considers how barriers to contact during pandemics can be managed, including access and use of online communication, limitations imposed by stroke-related disability, and how the experience of feeling supported and social identification can be better nurtured within remote contexts.

KEYWORDS

group support, loneliness, self-esteem, social identity, well-being

INTRODUCTION

Stroke is a leading cause of serious long-term disability among adults (Virani et al., 2020). Stroke survivors can be left with a wide range of challenges, including physical and cognitive impairment, communication difficulties, chronic fatigue, emotional lability and post-stroke depression and anxiety (Cumming et al., 2016; Flowers et al., 2016; Schöttke & Giabbiconi, 2015; Tatemichi et al., 1994; Wade & Hewer, 1987). These outcomes can have major implications both for day-to-day functioning and psychosocial health, including the ability to form and maintain new and existing relationships, increasing the likelihood of social isolation, loneliness, low self-esteem and well-being (Ch'Ng et al., 2008; Northcott et al., 2015; Petite et al., 2015). Recognizing these challenges, in 2015, the U.K. Stroke Association (SA) implemented a nationwide programme that aimed to scale up their existing network of peer-support groups for stroke survivors (Nesta, 2015). The programme aimed to provide a basis for stroke survivors to receive group-based social support within community groups and, through this, reduce loneliness and increase confidence and well-being (Dorning et al., 2016; Dworzynski et al., 2015; The Stroke Association, 2015). In 2019, there were more than 200 SA peer-support groups in the United Kingdom, meeting between weekly and once per month depending on the group, but their operation was severely compromised by the global COVID-19 pandemic (The Stroke Association, 2020).

Research has documented the negative impact of the COVID-19 pandemic on loneliness and psychological health, particularly among those with existing chronic health conditions (Alzheimer's Society, 2020), and a cross-sectional survey found that 69% of stroke survivors felt 'more anxious and depressed lately' during the early stages of the pandemic (The Stroke Association, 2020). The current study explored (i) how SA peer support groups have adapted to the pandemic and enabled continued contact as a group; and (ii) the relationship between stroke survivors' experience of shared social identity and perceived social support from the group and psychosocial outcomes during this time. In doing so, the study sought to understand how effective group-based support for stroke survivors might be maintained or enhanced in the future when in-person contact is limited or not possible.

THE SUPPORTIVE EFFECTS OF GROUP MEMBERSHIP

The SA's stroke support groups are commonly run by individuals who are themselves stroke survivors or have supported someone who is (in 2016, 72% of group facilitators were stroke survivors, Dorning et al., 2016). Before the COVID-19 pandemic, these groups provided members with a context for social interaction in a physical space through a range of activities built around a programme of peer support (Dorning et al., 2016). Group-based peer support, founded on shared health experiences, is associated with reductions in feelings of isolation and can promote feelings of empowerment in people living with a range of health conditions, including stroke survivors (Ketokivi, 2009; Tamplin et al., 2013). An earlier evaluation of these SA peer support groups before the pandemic showed that group members feel positive about being part of a group and report that their confidence, social networks, health and well-being benefitted from their participation (Dorning et al., 2016). Research around group-based social support and shared social identity provide a valuable framework for understanding these positive effects (Haslam et al., 2009; Northcott et al., 2015).

Current evidence suggests that such groups can provide *practical and emotional support* that facilitates coping among those with stroke and other chronic illnesses (Boothroyd & Fisher, 2010; Northcott et al., 2015). Peer-support groups have been described as providing a context for the normalization of experiences post-stroke, providing feelings of being understood, as well as acting as a space for acquiring understanding and practical knowledge (Ch'Ng et al., 2008; Christensen et al., 2019; Morris & Morris, 2012; Northcott et al., 2015). Greater social support after stroke has been shown to predict better functional and psychological outcomes (Glass et al., 1993; Northcott et al., 2015). In particular, 'perceived social support', which represents beliefs about the availability and adequacy of social support, has been shown to be predictive of health and well-being outcomes for different groups, including during the pandemic (Grey et al., 2020; McDowell & Serovich, 2007). This contrasts with measures of 'received social support' that instead indicate the frequency of supportive behaviours and less consistently show this relationship with outcomes (Grey et al., 2020; McDowell & Serovich, 2007). The contribution of perceived social support from stroke groups for stroke survivor well-being during a pandemic is less clear.

More broadly, a growing body of literature also evidences the ability for social groups to provide a source of *shared social identity*, whereby an individual sees the group as a part of their identity (Haslam et al., 2009; Haslam et al., 2018). Shared social identity provides a basis for the receipt and provision of social support within a group (Haslam et al., 2018) but may also provide independent benefits above and beyond this, such as a buffer against negative social stigma, promoting meaning and connection, allowing for positive social influence and nurturing a sense of collective efficacy (Haslam et al., 2018; Tarrant et al., 2020). Shared social identity has also been linked to reduced loneliness, depression and anxiety, as well as improved life satisfaction (Haslam et al., 2016; Haslam et al., 2019). Such health impacts are of particular relevance for stroke survivors whose pre-stroke self-concept may have been compromised by functional impairments and changes in activities (including potential loss of work and other social roles), relationships and personal image (Anderson & Whitfield, 2013; Salter et al., 2008). Participation in stroke groups may help stroke survivors to re-construct a positive identity (Northcott et al., 2015) and provide an important sense of belonging (Morris & Morris, 2012; Tamplin et al., 2013).

Although qualitative research shows both positive and some negative reports from stroke survivors about their experiences of attending stroke groups, including responses around the

importance of social support and shared social identity (Northcott et al., 2015), quantitative research to explore the association between these factors and well-being outcomes is lacking, even more so in the context of a pandemic.

PEER-SUPPORT GROUPS IN A PANDEMIC

On 23 March 2020, the United Kingdom introduced social distancing measures to reduce the number of infections of COVID-19 causing illness/death and impacting health services. The SA's network of peer support groups suspended in-person meetings from that point; however, a number of groups maintained contact with their members in other ways (e.g. using telephone, virtual group meetings and newsletters). Just one qualitative study has looked at the experiences of stroke groups during this time. This qualitative research with a virtual choir run for stroke survivors highlighted how these groups can provide a sense of belonging, but also the yearning of members to meet face-to-face and the limitations for those who are not able to use online technologies (Seckam & Hallingberg, 2021). Other research outside of the COVID-19 pandemic shows how remote forms of contact between stroke survivors, such as online forums, can provide valuable emotional support post-stroke (Smith et al., 2021). However, the current study was designed to extend this research to more broadly understand stroke survivors' experiences of perceived social support and shared social identity within stroke groups that would normally see and meet each other face-to-face (unlike online forums) but for a time are unable to do so.

The study documents group members' experiences of perceived social support and shared social identity with their stroke groups during the COVID-19 pandemic and associated psychosocial health (specifically, loneliness, well-being and self-esteem). In doing this, the study aimed to illuminate the functioning of peer support groups and how they might improve the service they provide for stroke survivors going forward—whether during other periods when face-to-face meetings are not possible or as a means to improve access to services for individuals unable to attend face-to-face groups due to health or geographical restrictions.

METHODS

Design

The study used both online and telephone-based surveys to administer scale-based and some open-ended questions to stroke survivors. Ethical approval for the study was provided by the senior author's institution (the University of Exeter College of Medicine and Health Research Ethics Committee, ref: Oct19/B/223), and all participants provided informed consent.

Participants

The SA stroke groups vary in size, frequency of meeting and activity (e.g. social, activity-based, such as art or exercise, or specifically for people with speech and language difficulties). Any member of these groups (including volunteer facilitators) was eligible to take part in the study as long as they were a stroke survivor and were over the age of 18. An opportunity sample was recruited with the purpose of involving as many stroke groups and members as possible.

Procedure

The survey was distributed between 16 June and 4 July 2020 (i.e. around 3 months into the COVID-19 pandemic). The survey was completed online (hosted by 'Qualtrics') or over the telephone. The survey link and telephone number were sent via email by SA directly to the 1376 stroke group members and 874 volunteer facilitators for whom contact permissions were in place. Group leaders were asked to forward the survey details using their contacts list and to share the researcher telephone details with group members not online.

Measures

Validated measures were used for group-based and outcome measures. Survey questions were supplemented with visual images and modifications to text formatting (larger text size, highlighting of key words) to support understanding and reduce burden commonly reported by this participant group (Cumming et al., 2016; Flowers et al., 2016; Stroke Association, 2012). Some demographic and personal variables, as well as the open-ended questions, were created for the purpose of this survey. The survey was reviewed by and tested with our advisory group of people with experience of stroke.

Demographic and personal variables

Participants reported their age (in years), gender (*male* or *female*), 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* (Bowling, 2005). Respondents' 'shielding' status was further 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*).

Several group demographics were also measured, including role within the group (*volunteer facilitator* or *member*), length of group membership (<12 months or ≥12 months) and frequency and mode of contact ('Thinking about your contact with other stroke group members, how often have you kept in contact during the COVID-19 pandemic by/using...'). Participants then reported the type of contact they had had with their stroke group by/using nine different formats (e.g. phone calls, emails and texting people individually; see Figure 1). Responses were given 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*). Finally, researchers calculated the number of days spent in pandemic restrictions at the point of survey completion.

Shared social identity and perceived social support

Participants were requested to answer questions with respect to their experiences 'during the COVID-19 pandemic'. Identification with their stroke support group was measured using the four item *Group Identification Scale* (GIS). Sani et al. (2015) designed this measure to be easy-to-understand and capture identification in a way that people would express

it in day-to-day parlance (e.g. 'I feel a bond with my group' and 'I feel similar to the other members of my group'). Responses were made on a 5-point scale (0 = *completely disagree* to 4 = *completely agree*) and a mean score calculated. A large ceiling effect was noted on this measure in our data, so a dichotomous variable was created that categorized responders as 'high identifiers' if their mean score was ≥ 3 for the subsequent regression modelling.

To examine perceived social support derived from their stroke group, participants completed the three-item *Oslo Social Support Scale* (OSSS-3) (Kocalevent et al., 2018), which asked: 'How many people in the group are so close to you that you can count on them if you have great personal problems?' (1 = 'none', 2 = '1-2', 3 = '3-5', 4 = '6+'); 'How much interest and concern do people in the group show in what you do?' (1 = *none*, 2 = *little*, 3 = *uncertain*, 4 = *some*, 5 = *a lot*); 'How easy is it to get practical help from the people in the group if you need it?' (1 = *very difficult*, 2 = *difficult*, 3 = *possible*, 4 = *easy*, 5 = *very easy*). Scores were summed in accordance with the scaling instructions, ranging from 3 to 14, with higher values indicating greater perceived social support.

Psychosocial outcomes: Well-being, loneliness and self-esteem

Well-being was measured using the *Shortened Warwick-Edinburgh Mental Well-being Scale* (SWEMWBS) (Stewart-Brown et al., 2009). This measure assesses mental well-being using 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*). The sum of scores was taken and then adjusted to a metric score using values provided by the authors of the scale (Stewart-Brown et al., 2009). Final scores can range from 7 to 35, with higher scores indicating greater well-being. Population data indicate that scores normally range from 22.9 to 23.7 in adult English samples with or without stroke (Koushede et al., 2019; Ng Fat et al., 2017).

Loneliness was assessed using the *Three-Item Loneliness Scale* (Hughes et al., 2004) adapted from the longer R-UCLA Loneliness Scale (Russell et al., 1980) for use in large population-based surveys. Items (e.g. 'How often do you feel that you lack companionship?') were rated on a 3-point scale (1 = *hardly ever*, 2 = *some of the time*, 3 = *often*), and responses to the three questions were summed and then dichotomized in line with recommendations (Campaign to End Loneliness, 2015; Steptoe et al., 2013) to distinguish individuals who are *lonely* (scores 6 to 9) versus *not lonely* (scores 3 to 5). Finally, global self-esteem was assessed using the single-item measure (Robins et al., 2001) 'I have high self-esteem', rated on a 5-point scale (0 = *completely disagree*, 4 = *completely agree*).

Open-ended questions

Open-ended questions relating to stroke group contact and support during the pandemic restrictions 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'.

Data analysis

Quantitative study variables were summarized and scale reliabilities assessed. Multi-level regression models separately explored the association of group identification ('high identifier' or not) and perceived social support during the pandemic restrictions for each outcome, in turn (logistic regression for loneliness, linear regression for well-being and self-esteem), accounting for the clustering of respondents within stroke groups. Unadjusted estimates were obtained from univariate models, and multivariate models provided estimates of the effects of the exposures adjusted for demographic and personal covariates for which there was at least weak evidence of an association ($p < .10$) in univariate models for that outcome. A priori calculations estimated that a sample size of 113 responses would be required to detect a Pearson's correlation coefficient of $\pm.3$ or greater with 90% power.

A qualitative description approach was taken for analysis of the open-ended responses (Bradshaw et al., 2017). This was an inductive approach, describing the data rather than testing pre-established theory. Thematic analysis was used to complete this qualitative description (Braun & Clarke, 2006), whereby two trained researchers (authors RL and LH) coded the full data independently using NVivo 12. Once independent analyses were completed, resulting codes were compared in a consensus meeting between the two researchers. Discrepancies in code names and relevant sections of text were discussed, and the primary researcher's (RL) codes modified to reflect the conclusions of these discussions. These were reviewed by two further authors (RC and MT) before confirming themes for final use. Overall, the analyses aimed to provide an overview of respondents' views and experiences relating to the contact they received from their stroke group during the pandemic restrictions and their thoughts on how stroke groups could improve remote group experiences in the future.

RESULTS

Sample characteristics

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). Group activity type and group meeting frequency are shown in Table 1; participant characteristics are described in Table 2. To test whether the online format of this survey had led to a sample less representative of stroke group members, age, gender, time since stroke and length of membership in the stroke group were compared with an earlier sample of stroke group members and volunteer facilitators taken from a paper-based survey with SA stroke groups.¹ This analysis confirmed that respondent characteristics did not differ significantly between the current sample and the paper-based survey sample.

Quantitative analyses

Stroke group contact during the pandemic

Most participants (87%) reported that they had maintained contact with their group during the pandemic. On average (median), respondents reported that they had used three different

TABLE 1 Group descriptives

SA geographical sub-zone	Central 1	$N_G = 17; N_P = 40$
	Central 2	$N_G = 22; N_P = 43$
	N Ireland	$N_G = 9; N_P = 19$
	North 1	$N_G = 2; N_P = 2$
	North 2	$N_G = 9; N_P = 20$
	North 3	$N_G = 5; N_P = 15$
	North 4	$N_G = 4; N_P = 11$
	South 1	$N_G = 21; N_P = 47$
	South 2	$N_G = 5; N_P = 9$
	South 3	$N_G = 11; N_P = 17$
	Scotland	$N_G = 5; N_P = 15$
	Wales	$N_G = 6; N_P = 14$
	Missing	$N_G = 2; N_P = 8$
	Frequency of group meeting	Weekly
Fortnightly		$N_G = 34; N_P = 69$
Monthly		$N_G = 31; N_P = 62$
Other		$N_G = 1; N_P = 1$
Missing		$N_G = 4; N_P = 12$
Group activity type	Support	$N_G = 83; N_P = 176$
	Speakability/aphasia	$N_G = 16; N_P = 41$
	Exercise	$N_G = 1; N_P = 2$
	Singing	$N_G = 2; N_P = 4$
	Creative arts	$N_G = 8; N_P = 13$
	Stroke cafe	$N_G = 5; N_P = 15$
	Other	$N_G = 1; N_P = 1$
	Missing	$N_G = 2; N_P = 8$

Note: N_G = number of groups; N_P = number of participants.

modes of contact to interact with their stroke group since closure. This included 62% making telephone calls, 60% emailing, 49% using text-based messaging, 47% using video calls and 25% using social media. The types and frequency (\leq once-a-month or $>$ once-a-month) of contact that stroke survivors had with their groups are shown in Figure 1. Under ‘other’, some respondents also noted that they had received postal mail (birthday cards, letters and newsletters).

Psychosocial outcomes

Table 3 reports bivariate correlations between key study variables. Well-being scores among stroke survivors during the pandemic ($M = 22.02$, $SD = 3.99$) were on average 1.59 points lower

TABLE 2 Sample characteristics ($n = 260$)

Age at T2 (years), mean (<i>SD</i>)	66.5 (10.4)
Gender, n (%)	
Male	143 (55.0)
Female	112 (43.1)
Non-binary	1 (0.4)
Missing	4 (1.5)
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)
Missing	3 (1.2)
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)
Missing	18 (6.9)
Overall health, n (%)	
Poor	16 (6.2)
Fair	96 (36.9)
Good	120 (46.2)
Excellent	18 (6.9)
Missing	10 (3.9)
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)
Missing	6 (2.3)
Days in lockdown, mean (<i>SD</i>)	88.7 (5.7)
Role in group, n (%)	
Member	161 (61.9)
Volunteer facilitator	90 (34.6)
Other	1 (0.4)
Missing	8 (3.1)

(Continues)

TABLE 2 (Continued)

Length of group membership (months), <i>n</i> (%)	
<1	1 (0.4)
1–2	4 (1.5)
3–6	9 (3.5)
7–12	32 (12.3)
12+	207 (79.6)
Missing	7 (2.7)

than the national average for adults more widely before the pandemic ($t = 6.35$, $df = 7444$, $p < .001$) (Warwick Medical School 2021). Respondents had a mean self-esteem score of 2.17 ($SD = 1.07$), and 41.5% of respondents stated that they were ‘lonely’ (53.5% ‘not lonely’, 5% missing data).

Group processes and psychosocial outcomes

Associations between shared social identity and perceived social support, and stroke survivor well-being, loneliness and self-esteem were tested. Table 4 presents the estimated effects from univariate regression models, fitted to loneliness, well-being and self-esteem. Having good/excellent subjective health relative to poor/fair health (3.55, $p < .001$, 95% CI 2.62–4.47), being a volunteer facilitator as opposed to a group member (−1.11, $p = .03$, 95% CI −2.14 to −0.09) and (weakly) shorter length of group membership was associated with higher well-being.

Higher social identification (−0.62, $p = .020$, 95% CI −1.15 to −0.10) and, to a lesser extent, greater perceived social support (−0.01, $p = .053$, 95% CI −0.02 to 0.00) were both associated with lower levels of loneliness. Living alone, worse subjective health, role within the group (being a member) and (weakly) longer length of membership within the group were also associated with greater loneliness. Higher social identification (0.25, $p = .047$, 95% CI 0.00–0.50) and perceived social support (0.01, $p = .044$, 95% CI 0.00–0.01) were associated with greater self-esteem, as was having good/excellent subjective health, being a volunteer facilitator and a weaker association with older age and less time in lockdown.

Multivariate analyses were conducted to examine shared social identity and perceived social support as predictors of loneliness, controlling for living situation, subjective health, role in the group and length of group membership (Table 5). High social identifiers (odds ratio [OR] 0.58, $p = .061$, 95% CI 0.33–1.02) and those with greater perceived social support (OR 0.99, $p = .065$, 95% CI 0.97–1.00) had a reduced risk of loneliness, although these effects were weaker than those for the effects involving living alone and worse subjective health.

Multivariate analyses were then completed looking at shared social identity and perceived social support as predictors of self-esteem, controlling for age, days spent in the pandemic restrictions, subjective health and role in the group (Table 5). Greater perceived social support was associated with higher self-esteem (0.00, $p = .052$, 95% CI 0.00–0.01), but no association was found with social identification (0.20, $p = .114$, 95% CI −0.05 to 0.44). Better subjective health predicted higher self-esteem, with weak evidence for an effect of older age.

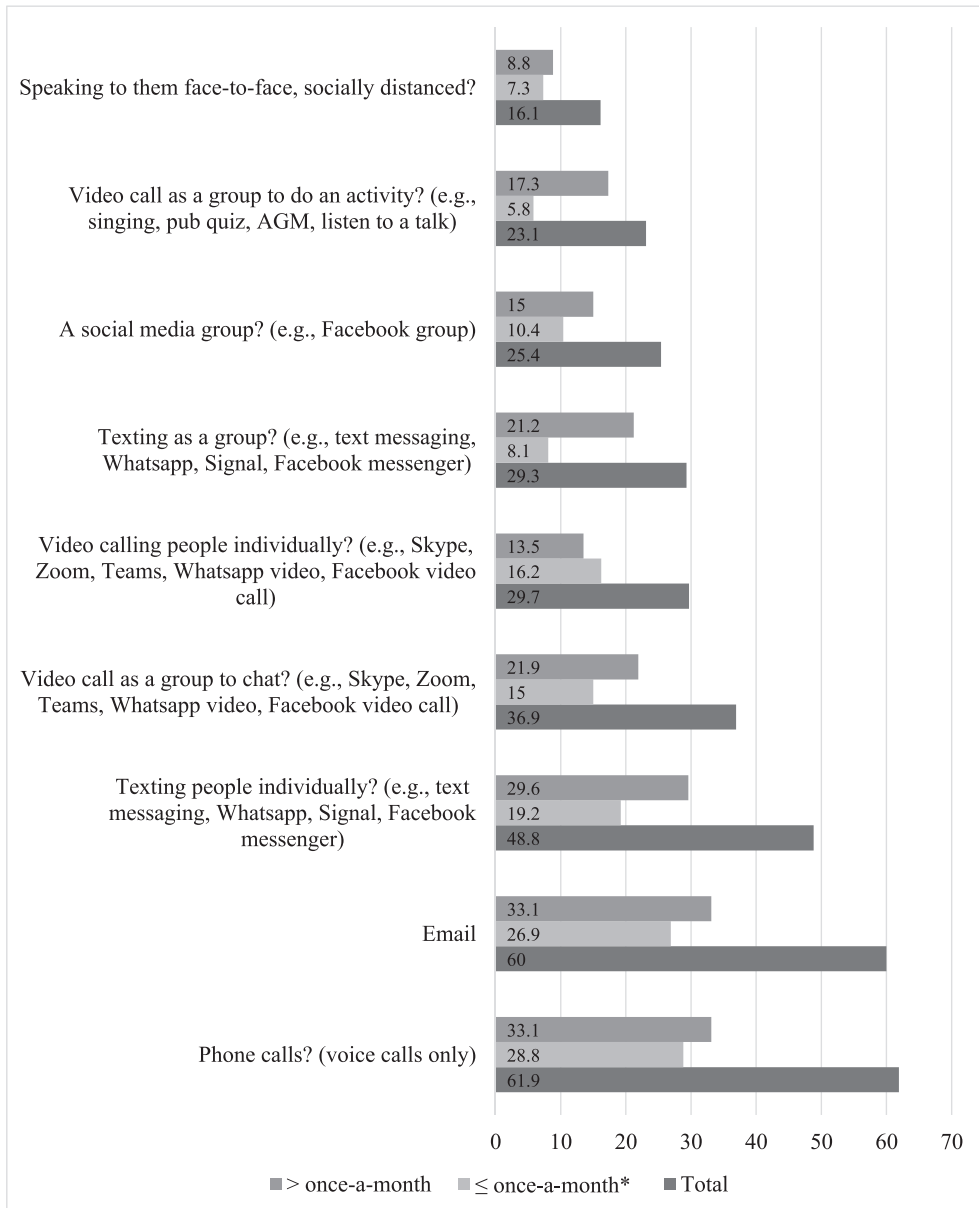


FIGURE 1 Type and frequency of contact with stroke groups (percentage of respondents). *Not including 'not at all'

Qualitative analyses

Most members (57%) suggested that their stroke group was adequately supporting them during the pandemic, but a third (33%) thought that their group could do more in this regard (10% did not answer this question). Open-ended responses (given by between 45% and 98% of respondents) provided further insights into stroke group members' experiences of contact and support

TABLE 3 Correlations between key study variables

	Social identification	Social support	Well-being	Loneliness ^a	Self-esteem
Social identification	1				
Social support	.50 (<.001)	1			
Well-being	.08 (.158)	.09 (.153)	1		
Loneliness ^a	-.15 (.050)	-.20 (.027)	-.63 (<.001)	1	
Self-esteem	.11 (.071)	.13 (.055)	.66 (<.001)	-.46 (<.001)	1

Note: Correlation coefficients (and associated *p* values) were obtained as appropriate from Pearson's correlations (continuous by continuous), polyserial correlations (continuous by ordinal), polychoric correlations (ordinal by ordinal) and tetrachoric correlations (dichotomous by dichotomous).

^aDichotomized.

from the group during the pandemic. Responses clustered around the themes of the contact figure, the nature of contact and support and perceived barriers (Figure 2 presents illustrative quotes).

Contact figure

Several respondents described wanting 'more contact', 'more communication', to 'keep in touch more' with other group members. The use of 'more phone calls' was often mentioned as a solution to this. Respondents reported that any ongoing contact with the group was primarily with the group leader or a volunteer facilitator and that it was these individuals who initiated contact. Contact between group members themselves (i.e. not initiated by the group leader or volunteer facilitators) was less often mentioned. Several respondents suggested a need for more contact between group members and similarly the need for formal facilitation of this through the group leadership. For example, participants suggested that encouraging smaller, sub-groups of members that can 'buddy' for additional support alongside whole-group contact could help meet their contact needs.

Nature of contact and support

Contact was most often described as 'keeping in touch' or 'checking-up'. Part of this was receiving group updates and newsletters and involved individual telephone contact from the group leader or volunteer facilitators and group video calls online. Less frequently, participants reported that their groups maintained contact through online activities such as singing, physical activity and physiotherapy, quizzes and puzzles, sharing art/creations and committee meetings. Contact within groups was sometimes described as a means by which members could receive practical and informational support, whether that be actual or potential (i.e. knowing there was someone members could ask for help). More commonly, contact was regarded as a basis for receiving emotional support, including helping members cope with challenges and sharing fun and humour. One volunteer facilitator articulated that it was important 'Just to know we are feeling the same in lockdown'.

TABLE 4 Estimated effects of perceived social support and social identification on loneliness, well-being and self-esteem, univariate analyses

	Well-being Coefficient (95% CI)	p value	Loneliness Coefficient (95% CI)	p value	Self-esteem Coefficient (95% CI)	p value
High social identification	0.69 (−0.25 to 1.64)	.151	−0.62 (−1.15 to −0.1)	.020	0.25 (0.00–0.50)	.047
Social support	0.01 (−0.01 to 0.04)	.242	−0.01 (−0.02 to 0.00)	.053	0.01 (0.00–0.01)	.044
Age (years) at T2	0.01 (−0.03 to 0.05)	.711	0.00 (−0.03 to 0.02)	.885	0.01 (0.00–0.02)	.058
Female gender	−0.32 (−1.26 to 0.63)	.514	−0.35 (−0.90 to 0.20)	.209	−0.17 (−0.44 to 0.10)	.214
Days in lockdown	0.01 (−0.09 to 0.11)	.843	0.01 (−0.05 to 0.06)	.807	0.02 (0.00–0.04)	.069
Lives alone	0.27 (−0.72 to 1.26)	.592	0.77 (0.12 to 1.42)	.020	0.08 (−0.25 to 0.42)	.636
Time since stroke						
0–2 years	Reference group	n/a	Reference group	n/a	Reference group	n/a
3–5 years	−0.01 (−1.41 to 1.40)	.994	−0.40 (−1.11 to 0.31)	.265	0.09 (−0.29 to 0.47)	.631
6–10 years	−0.17 (−1.46 to 1.11)	.793	−0.22 (−0.98 to 0.54)	.576	0.08 (−0.28 to 0.43)	.674
>10 years	0.78 (−0.68 to 2.24)	.294	−0.33 (−1.07 to 0.40)	.377	0.09 (−0.31 to 0.48)	.669
Overall health						
Poor/fair	Reference group	n/a	Reference group	n/a	Reference group	n/a
Good/excellent	3.55 (2.62–4.47)	<.001	−1.28 (−1.92 to −0.64)	<.001	0.72 (0.46–0.97)	<.001
Received 'shielding' letter						
No	Reference group	n/a	Reference group	n/a	Reference group	n/a
≥1 in household	−0.79 (−1.88 to 0.31)	.158	−0.23 (−0.94 to 0.48)	.523	0.03 (−0.27 to 0.33)	.841
Role in group						
Volunteer facilitator	Reference group	n/a	Reference group	n/a	Reference group	n/a
Member	−1.11 (−2.14 to −0.09)	.034	0.75 (0.16–1.33)	.013	−0.36 (−0.63 to −0.1)	.007
Other	−0.47 (−1.33 to 0.39)	.283	Excluded ^a	n/a	−0.4 (−0.62 to −0.19)	<.001
Length of group membership						
<12 months	Reference group	n/a	Reference group	n/a	Reference group	n/a
≥12 months	−1.29 (−2.73 to 0.14)	.078	0.71 (−0.05 to 1.46)	.066	−0.17 (−0.51 to 0.17)	.329

^a‘Other’ role in group was excluded from this model due to issues of multicollinearity.

Perceived barriers

Some participants reported no (or minimal) contact with their group, either out of personal choice or because they were unaware of or unable to engage in contact opportunities. For the latter, whereas most participants had ready access to technology required to maintain ‘virtual’ contact (internet access, smart phone), several participants reported access difficulties or difficulties using technology as a barrier to their or other members’ participation. Stroke-related disability was also cited by some as a reason for not maintaining contact with the group, with

TABLE 5 Estimated effects of perceived social support and social identification on loneliness and self-esteem, controlling for demographic variables, multivariate analyses

	Model 1: Group identity		Model 2: Social support	
Loneliness	Odds ratio (95% CI)	<i>p</i> value	Odds ratio (95% CI)	<i>p</i> value
High social identification	0.58 (0.33–1.02)	.061	n/a	n/a
Social support	n/a	n/a	0.99 (0.97–1.00)	.065
Lives alone	2.56 (1.19–5.51)	.016	2.49 (1.13–5.49)	.024
Overall health				
Poor/fair	Reference group	n/a	Reference group	n/a
Good/excellent	0.28 (0.14–0.57)	<.001	0.29 (0.14–0.58)	.001
Role in group				
Volunteer facilitator	Reference group	n/a	Reference group	n/a
Member	1.60 (0.87–2.95)	.133	1.58 (0.83–3.01)	.162
Length of group membership				
<12 months	Reference group	n/a	Reference group	n/a
≥12 months	1.53 (0.70–3.35)	.287	1.45 (0.64–3.25)	.373
Self-esteem	Coefficient (95% CI)	<i>p</i> value	Coefficient (95% CI)	<i>p</i> value
High social identification	0.20 (–0.05 to 0.44)	.114	n/a	n/a
Social support	n/a	n/a	0.00 (0.00–0.01)	.052
Age (years) at T2	0.01 (0.00–0.02)	.071	0.01 (0.00–0.02)	.043
Days in lockdown	0.02 (0.00–0.04)	.079	0.01 (–0.01 to 0.04)	.212
Overall health				
Poor/fair	Reference group	n/a	Reference group	n/a
Good/excellent	0.72 (0.45–0.98)	<.001	0.71 (0.45–0.96)	<.001
Role in group				
Volunteer facilitator	Reference group	n/a	Reference group	n/a
Member	–0.19 (–0.45 to 0.07)	.150	–0.20 (–0.47 to 0.07)	.140
Other	–0.32 (–0.63 to –0.01)	.043	–0.41 (–0.7 to –0.13)	.005

participants reliant on family members or carers to facilitate their contact with the group, which was not always available. Finally, several respondents mentioned not knowing the group well or feeling insufficiently close to its members prior to the pandemic as a barrier to current contact.

DISCUSSION

The COVID-19 global pandemic has presented challenges about how follow-up care and ongoing support can be organised and provided for stroke survivors (The Stroke Association, 2020). Prior to the pandemic, the United Kingdom most prevalent form of support for stroke survivors was provided through face-to-face group meetings, which also provided opportunities for the formation of meaningful social connection between members (Dorning et al., 2016). The current study provides insights into how support for stroke survivors has continued and how it has been experienced by members of stroke support groups during the COVID-19 global pandemic.

<p>Contact with whom</p> <p><i>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]</i></p> <p><i>Volunteer rings once a week [member]</i></p> <p><i>Being more willing and proactive in contacting each other [volunteer facilitator]</i></p> <p><i>I would have kept in contact with people more but don't have their numbers. The leader has been great at keeping in contact though [member]</i></p> <p><i>Introduce a buddying system so we are ready for the next crisis [volunteer facilitator]</i></p> <p><i>Putting like minded/similarly experienced people in touch with one another for support [member]</i></p>
<p>Nature of contact and support</p> <p><i>Our co-ordinator, [name redacted], phones round the members on a regular basis and keeps us in touch with how the others are keeping. [member]</i></p> <p><i>[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]</i></p> <p><i>Yes... She phones me every fortnight to enquire how I'm doing [member]</i></p> <p><i>Phone calls to check on each other [member]</i></p> <p><i>We have a monthly news letter sent out by email which is a nice way to keep in touch with the group. [member]</i></p> <p>Activities</p> <p><i>We chat on zoom and do a little quiz every Thursday [member]</i></p> <p><i>Talking to each other during the weekly Zoom meetings and sharing images of our artistic enterprises: painting, drawing, needlework, photography. [member]</i></p> <p><i>Helpful to have a zoom exercise meeting each week [member]</i></p> <p><i>Fund raising discussions among committee members mostly secretary and treasurer. [volunteer facilitator]</i></p> <p>Practical and informational support</p> <p><i>Two of us have contacted the more venerable members to see if they are ok and to signpost them for help if required. [volunteer facilitator]</i></p> <p><i>They are so positive and so helpful and do anything they can to be there for their members. [member]</i></p> <p><i>Just making sure everyone's ok and if we need anything thing can be put in place. [member]</i></p> <p>Emotional support</p> <p><i>Regular video meetings to share concerns, Hoots (funny things), Hurrahs (Celebrations eg birthdays, back to work, etc) Horrors (things that may have gone wrong and where sharing can help individual and group). [volunteer facilitator]</i></p> <p><i>I get a call from the leader once a fortnight and they called me when I went into hospital. I call one of the ladies every other week who I know better as she can get down sometimes. [member]</i></p> <p><i>Sadly two members have died during the lockdown and the sad news travelled quickly - Volunteers have been in touch with their families and sent condolences from the group. [member]</i></p>
<p>Perceived barriers</p> <p>Access and use of technology</p> <p><i>we are trying to launch a newsletter to contact those (sadly, the majority) who have no IT or mobile phones. [volunteer facilitator]</i></p> <p><i>Unfortunately a good many of the [name redacted] Club members are not able to join us as their skills or equipment is not up to making this possible. [volunteer facilitator]</i></p> <p><i>Fortnightly Skype although I couldn't join due to technical problems [member]</i></p> <p><i>It would be nice to have Zoom chats but not enough members are comfortable with Zoom for the group organisers to arrange it [member]</i></p> <p><i>help those who don't have / want digital access, join in video meetings. But would need to supply tablet, internet access, train in use of tablet. Difficult to do remotely [member]</i></p> <p><i>Video / zoom / Facetimeing etc. unfortunately most are elderly and are not conversant in this new technology [volunteer facilitator]</i></p> <p><i>arrange group zoom coffee mornings perhaps [volunteer facilitator]</i></p> <p>Disability and support</p> <p><i>If I am able to get people on the phone we usually have a good natter, but it is limited by their disability which often means it is short and sweet! [volunteer facilitator]</i></p> <p><i>They would find it difficult to support each other due to their disabilities. [member]</i></p> <p><i>Unable to keep in touch as unable to use a phone, text or video call I have aphasia [member]</i></p> <p><i>Phone call to my wife - I have severe aphasia, so cannot use the phone. [member]</i></p> <p><i>Someone is inputting this information on my behalf and about a couple of local issues recently he was able to send an email on my behalf to the person who runs our group. [member]</i></p> <p>Closeness to the group</p> <p><i>I don't know the group very well, only be going to the group once a month. Some of the group having going a while and have been supporting other members of the group. [member]</i></p> <p><i>Before the pandemic, I went to a few meetings, a bbq, a Christmas party and a monthly get together for a walk in a local park. Overall though, the group members do not appear close personally and I do not think it is set up to offer support between members, which is fine. Obviously, staff are there to offer support. [member]</i></p> <p>Face-to-face contact</p> <p><i>I do not live near enough to anyone else for the group to be of much use to me. [member]</i></p> <p><i>Most people apart from the afore mentioned have been shielding and so cannot have visitors. Now that they can, the few I have managed to speak to, want family in their bubble and not Stroke volunteers currently. Which is understandable! [volunteer facilitator]</i></p>

FIGURE 2 Qualitative extracts

Peer-support groups during the pandemic

The findings indicate that 87% of stroke survivors sampled had continued to engage with their stroke group during the early part of pandemic restrictions and that overall levels of social identification with groups were high. This contact took a range of formats, most commonly telephone calls and online engagement (e.g. email and video calls). Difficulties using or accessing required technology and absence of pre-existing sense of connectedness to the group were barriers to participation and may account for some of the 13% of participants who did not engage with their group during the early part of the pandemic.

Well-being, loneliness and self-esteem

Overall well-being among participants during the pandemic was lower than that of the national average for adults more broadly (non-stroke included) outside of pandemic times. Well-being was most clearly associated with better subjective health and participant role within the group (higher for volunteer facilitators rather than members). For loneliness, living status and subjective health, and to a lesser extent shared social identity and perceived social support from the group, were all correlates, as might be expected. Indeed, ORs indicated that those participants reporting that they had 'poor/fair' health were 1.72 times more likely to say that they were lonely than those with 'good/excellent' health, and those that lived alone were 2.56 times more likely to be lonely. Finally, perceived social support, age and subjective health were all associated with higher self-esteem, with strongest effects for subjective health.

As outlined earlier, stroke support groups provide an opportunity for stroke survivors to (re-) establish social connections with other people and develop meaningful social identities which may support rehabilitation (Haslam et al., 2018). While the contribution of social variables (perceived social support from and identification with the stroke support group) was less marked than for other variables assessed here—particularly subjective health—it is notable that these effects for social identity processes were observed around 3 months into pandemic restrictions—that is, in the absence of any physical contact with the groups. Other sources of social support (for example from other groups such as family or friend networks) were not measured here, but these may have been a more prominent contributor to participants' psychosocial health at this time (Haslam et al., 2016, 2008). It may be that, despite the stroke support groups continuing to be an important basis for self-definition, as indicated by the high levels of social identification with the groups, the contribution of the identity processes that flow from this specific group membership is reduced following major disruptions to in-person contact with other group members.

Implications for post-stroke support in a pandemic

Extracts from the open-ended survey questions showed that contact with stroke support groups during the pandemic was experienced as qualitatively different from in-person contact, notably that it did not typically include contact with group members and was more 'light touch' in nature. From a practical standpoint, it may be prudent to identify ways in which group members can be supported to maintain meaningful contact with each other, characterized by social interaction, even when groups do not meet in-person. The social identity approach emphasizes the importance of encouraging interaction between group members that is characterized by

cooperation, trust, involvement, shared goals and identity (Tarrant et al., 2020). Mechanisms for recreating these important shared experiences in online environments could be explored. Promotion of member-to-member and smaller group online connections may lay the foundations for wider group-based activity, overcoming the reported lack of familiarity some newer members felt with the group. Equally, larger group-based meetings might seek to involve aspects of shared planning and activity to encourage online cooperation and sharing of experiences.

The finding that stroke survivors who lived alone and who were in (relative) worse health were at greatest risk of experiencing loneliness, low self-esteem and poor well-being highlights the potential benefit of more targeted support through stroke groups and other means to ensure these individuals receive priority support. This will involve identifying solutions to barriers associated with remote group-based communication, which particularly affect those in worse health or without friends or family around to support them, for example, in the use of the internet for email, video calls and social media. Those aged 65+ still consistently make up the largest group of adults not using the internet (Office for National Statistics, 2019).

Limitations

Despite the large sample and wide reach of the study (260 stroke survivors from 118 groups across the United Kingdom), several limitations are noteworthy. 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 biasfounded the sample towards respondents who have or can be supported to use the internet. These individuals may be more adept at maintaining (or initiating) contact with others when in-person meetings are not possible. Accordingly, the relatively high levels of shared social identity reported here may not generalize to other stroke survivors.

As noted above, the various other possible social groups that people identified with and received support from during the pandemic were not assessed here. Other group memberships may have become a stronger or more salient well-being resource to which participants turned during this time when SA groups were no longer able to meet face-to-face. Future research should consider the potential impacts of these wider, multiple, group memberships on stroke survivors' health and well-being. Moreover, as is common in applied research such as this, we made several minor modifications to the format of study measures in order to aid participant understanding, but it is recommended that future research test the validity and reliability of these. Finally, as this research is cross-sectional, inferences about causal pathways should not be made.

CONCLUSIONS

This survey of 260 stroke survivors from 118 different peer-support groups across the United Kingdom found that the groups had adapted to the COVID-19 pandemic by replacing in-person contact with telephone calls and a range of internet-based modes of contact. While this contact was largely limited to contact with group leaders or volunteers, rather than with other group members, participants continued to value their membership in their stroke support

groups. Subjective health and living status were associated with the psychosocial health outcomes of well-being, loneliness and self-esteem, with a lesser role here for shared social identity and perceived social support from the stroke support groups. Improving access to and use of online tools for communication among stroke survivors, as well as considering how experiences of group-based social support and shared social identity can be effectively managed in a remote context, are identified as priorities for future research.

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CONFLICT OF INTEREST

All authors report the Stroke Association funding for the work under consideration but no other conflicts of interest.

DATA AVAILABILITY STATEMENT

The study data have not been made available. Participants did not consent for datasets to be stored or accessed outside of the research team.


ETHICS APPROVAL

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

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ENDNOTE

ⁱ At the start of the COVID-19 pandemic, demographic data using these same stroke support groups were collected as part of a wider study for the Stroke Association. The same inclusion/exclusion criteria had been applied, although that survey was administered in paper format during face-to-face group meetings. Here, we refer to a comparison with the demographics of this pre-pandemic sample of 565 stroke survivors.

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