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Experiences of an online version of a group education programme for the management of post-stroke fatigue: A qualitative descriptive focus group study

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ABSTRACT


Post-stroke fatigue (PSF) is a common symptom after stroke, without proven effective treatment. The Fatigue After Stroke Educational Recovery (FASTER) randomized control trial evaluated a group-based, educational Fatigue Management Group (FMG) intervention. The current study explored the experiences of stroke patients, informal caregivers, and therapists when the FMG was delivered online (due to the COVID-19 pandemic). Participants included newly recruited adults ($n=6$) with clinically significant fatigue (3–24 months post-stroke), their informal caregivers ($n=6$), who attended as observers, and three therapists from the FASTER main trial. Separate online focus groups were conducted with each group, recorded, and analysed using inductive thematic analysis. Four key themes emerged: positive experiences of group membership, gaining understanding and strategies, navigating challenges in online setting, and future directions. Participants acknowledged the intervention for its educational value, normalization, cohesion, and emotional support, and appreciated new understanding of PSF. However, they also encountered challenges, including technological issues, difficulties concentrating, and therapists' struggles in addressing diverse participant needs and fatigue levels within time constraints. Suggested improvements to the intervention included extending its duration and including combinations of online and in-person sessions. Findings highlighted the importance of qualitatively examining intervention experiences in future trials for better optimization and effectiveness.

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Introduction

Post-stroke fatigue (PSF) refers to abnormal/pathological fatigue characterized by weariness unrelated to previous exertion and not ameliorated by rest (McGeough et al., 2009). PSF is recognized as the most disabling complaint post-stroke, affecting at least 50% of patients (Barbour & Mead, 2012), with adverse impacts on quality of life, work activities, social involvement, and sleep (White et al., 2012). Global stroke guidelines recommend stroke patients and their families/carers should be provided with education and strategies to manage PSF (Cameron et al., 2022; World Stroke Organization, 2017), yet there are no proven treatments available (Wu et al., 2015). Cognitive Behavioural Therapy (CBT) is a form of psychotherapy that focuses on the identification and modification of unhelpful thoughts and behaviour patterns (Beck, 1995). Group-based CBT for fatigue has been found helpful in other health conditions (e.g., multiple sclerosis) (van den Akker et al., 2018), with evidence of comparable treatment effects of CBT when delivered in-person or online (Adhikary et al., 2023; Worm-Smeitink et al., 2019). Advantages of group-based CBT include sharing goals, enhanced motivation and engagement, and learning from each other (Zandieh et al., 2024).

Partially informed by CBT, the “Fatigue After STroke Educational Recovery” (FASTER) study was a prospective, multi-centre, two-arm, single-blinded, phase III (parallel, superiority) randomized controlled trial (Barker-Collo et al., 2022). Participants ($n=200$) included adults who had experienced a stroke within the past 3–24 months and clinically significant fatigue. Participants were randomized to general stroke education/control or fatigue management group (FMG) intervention. The FMG involved 60–90-min weekly psychoeducation sessions delivered over six weeks with an emphasis on the importance of participant contributions and encouragement of a self-management philosophy. Participants’ informal caregivers were also invited to attend intervention or control education sessions in an observer capacity. Participant outcomes were assessed at baseline, 6-weeks, and 3-months. Co-primary outcomes were Fatigue Severity Scale (FSS) and Multidimensional Fatigue Inventory-20 (MFI-20) total scores. Results showed no significant group-level effects of the FMG intervention on primary outcomes, being self-reported physical and multidimensional fatigue immediately post-intervention (6 weeks) and at 3 months. Adjusted mean total Fatigue Severity Scale (FSS) scores at 6-weeks (primary endpoint) were nearly identical for control and FMG groups. The adjusted mean difference between treatment groups was -0.13 (SE, 1.4; $P=.92$) at 6 weeks and 1.67 (SE, 1.4; $P=.26$) at 3 months. However, while non-significant, physical fatigue outcomes were in the direction of a treatment effect consistent with the initial pilot study (Clarke et al., 2012). Adjusted mean total MFI-20 scores at 6-weeks were also similar for control and FMG groups. The adjusted mean difference between treatment groups was -0.91 (SE 1.54, $P=.55$) at 6-weeks and

–1.26 (SE 1.8, $P = .49$) at 3-months. Both groups also had similar secondary outcomes (e.g., MFI-20 subscales, sleep, pain, mood, quality of life) at 6-weeks and 3-months (Jones et al., 2025). The authors of the FASTER study concluded that educational, group-based interventions for PSF may hold promise; further refinement is needed to address the unique challenges faced by stroke survivors and to explore individual-level benefits of such interventions.

The current qualitative study, an extension of the FASTER study, qualitatively sought to better understand end-user experiences of an online version of the FMG intervention from the perspectives of adults participating in the intervention (stroke patients), adults observing the intervention (informal caregivers) and those with experience delivering the intervention in-person in the FASTER study (therapists). Feedback from participants about potential improvements or modifications to the intervention (e.g., content, format) was also requested to inform future research in this area.

Methods

This study used a descriptive qualitative methodology and research design to capture subjective feelings, perceptions and meanings contextually tied to experiences of the intervention (Magilvy & Thomas, 2009; Neergaard et al., 2009). The main findings of the trial are published elsewhere (Jones et al., 2025). Ethical approval was granted by the Auckland University of Technology Ethics Committee (reference 21/323).

Research team and reflexivity

Eight researchers contributed to the study (six women – five with doctorates and one doctoral student – and two men with doctorates), from the fields of health science, biomedical science, psychology, and clinical neuropsychology. VF is an experienced clinician and researcher in Stroke. RK, KJ, SB, KV and BT are experienced stroke researchers, and were responsible for study design and processing along with SD, to reduce the study bias. Focus groups were co-facilitated by two female researchers, one being a trained public health researcher (CC – Master's in Health Science) and the other being the FASTER study manager (SD – Doctorate in Biomedical Science). SD, KJ, KV, and AB (doctoral student) were involved with data analysis.

Participant recruitment

Three groups of participants took part in the current study: stroke patients, informal caregivers; and therapists experienced in delivering the FMG intervention. (1) Stroke patient recruitment: To minimize risk of overburdening participants with PSF taking part in the main FASTER trial, a new sample of stroke

patients and their informal caregivers were recruited for the current study. These stroke participants took part in the FMG intervention but were not assessed as part of the main trial. Potential participants with stroke were identified from an existing stroke trial registry from the ARCOS-V study (Feigin et al., 2020). Stroke patients were recruited using purposive sampling for age [<65 ; $65+$], sex, disability [modified Rankin Scale (mRS) 0–1; 2–3], and ethnicity (Māori; non-Māori) to reflect stroke patient diversity. Consistent with the main FASTER trial, inclusion criteria were: aged ≥ 18 years with clinically diagnosed stroke (CT/MRI confirmation of stroke pathological type) in the past 3–24 months; clinically significant fatigue (score ≥ 12 on the self-report Multidimensional Fatigue Inventory (MFI-20) general subscale); residing in the study area; ability to converse in English (including patients with mild expressive aphasia); and informed consent to participate. Exclusion criteria were: pre-stroke fatigue; significant disability; cognitive/behavioural impairments; a medical condition precluding participation; other causes of fatigue; and/or participation in another trial (Barker-Collo et al., 2022; Jones et al., 2025). (2) Informal caregiver recruitment: Stroke patients who were eligible and consented to take part in the current study could invite an informal caregiver (aged >15 years, defined as an unpaid person who helps with daily activities ≥ 1.5 h/week) to also take part in the study. (3) Therapist recruitment: Therapists were registered clinical psychologists with experience in delivering the FMG intervention through their involvement in the main FASTER trial.

Potentially eligible stroke patients were contacted via phone by a member of the study team. Those interested in the study were sent an email invitation, with a study information sheet and consent form, and re-contacted after one week to discuss the study further. Where relevant, potential participants were screened for all study criteria. Therapists were invited by email to take part and were provided a study information sheet and consent form.

Intervention: FMG programme (online version)

All aspects of the intervention mirrored the main FASTER trial, with the expectation that in-person delivery of the intervention was changed to online delivery due to the COVID-19 pandemic and associated restrictions. Stroke patients attended six-weekly (60–90 min) online group FMG sessions focused on PSF management. Informal caregivers attended the same online sessions, with their family member with stroke, over the six-week period, but in an observer capacity only. Therapists had no expectations of caregivers who were only required to observe group sessions. The sessions covered key topics, including an introduction to fatigue (week 1), fatigue management (week 2), sleep/relaxation (week 3), exercise and nutrition (week 4), mood (week 5), and future strategy use (week 6). Week 5 focused on reviewing a cognitive behavioural model of mood/fatigue. This model is commonly referred to as a 4- or 5-part model

(depending on whether the “situation” to which the model is applied is considered part of the model itself) (Padesky, 2020; Wright et al., 2002). This session focused on the four other aspects of the model, thoughts, emotions, behaviours, and physical sensations, and how each of these can contribute to mood and post-stroke fatigue.

Sessions aimed to explain what PSF is and why it occurs; aid understanding of personal fatigue and its relation to activity levels; identify factors that exacerbate PSF; introduce strategies to help manage PSF; and help participants in identifying the most useful strategies for them within a supportive group environment. Each online session followed traditional CBT structure of agenda setting, reviewing previous sessions and tasks, and presenting new information followed by examples from daily life, guided practice in strategy use, and group activities.

Before the first FMG session, participants were emailed a booklet, including information to accompany each session, and a fatigue and activity diary. Material included in each session was intended to be realistic and relevant to participant needs and this was achieved by encouraging them to generate examples from their own experience. Each session was run by a registered clinical psychologist with experience in evoking change in a patient’s life in a short period of time. The brief CBT framework focused on compensatory strategies, such as energy conservation, to address the likely original factors contributing to PSF. The group process recognized the expertise of the members, validated their experiences, and enabled the sharing of knowledge, reflection, and experiences. The aim of behaviour change was facilitated by goal setting, planning, and trialling fatigue management strategies in the home and community. The therapists followed a manualized treatment protocol involving didactic teaching, group activities, and discussions (see Table 1 for overview of content of FMG sessions). In addition, stroke patients completed a daily diary recording PSF frequency, duration, and self-perceived causes for personal review and reflection.

Table 1. Fatigue Management Group (FMG) session content.

FMG session	Session title	Content overview
1	Overview, introduction to fatigue	Overview, discuss stroke experiences, define fatigue, introduce fatigue diaries
2	Fatigue management	Review diaries, PSF education (e.g., causes), fatigue management strategies
3	Sleep/relaxation	Review homework/diaries, discuss sleep patterns/sleep hygiene, stress, relaxation exercises
4	Exercise and nutrition	Review homework/diaries, impact, and relation of exercise and nutrition to fatigue
5	Mood	Review of homework/diaries, cognitive behavioural model of mood and fatigue
6	Future focus	Review homework/diaries review course, future strategy use

Given the current study focused on experiences of the intervention itself, participants in this study did not complete the baseline and follow-up measures included in the FASTER trial. Furthermore, stroke patients maintained daily diaries to check frequency, duration, and self-perceived causes of PSF, for personal review and reflection.

Data collection

Three separate online focus groups for each type of participant (stroke patients, informal caregivers, therapists) were conducted. Focus groups with stroke patients and caregivers were held on the same day to reduce burden on participating families. Focus groups were used to allow participants to build on each other's ideas, which can lead to more in-depth conversations, and because they provide a timely and inexpensive way to gather information from multiple people.

Each focus group lasted 60–75 min. Following a brief overview of the purpose of the project and focus group, two warm-up questions were discussed, followed by six to eight semi-structured questions (see Interview Guide Appendix 1). Within each focus group, discussions continued until data saturation was reached. The determination that saturation had been reached was evaluated in real-time by the facilitators when no new insights or themes emerged from each of the separate discussions and further confirmed through iterative review of field notes and audio recordings, ensuring the decision was based on the absence of new themes rather than mere repetition (information redundancy). Focus group discussions were audio recorded and transcribed verbatim by the first author, using Microsoft Word 360. Alongside this, field notes were taken during each focus group session. All participants (stroke patients, their informal caregivers and therapists) attended an online focus group, except one stroke patient and their caregiver who were unavailable due to personal reasons and later participated in individual Zoom interviews.

Data analysis

Inductive thematic analysis (TA), a process of coding data without trying to fit data into a pre-existing coding frame or the researcher's analytic preconceptions, was used to identify themes and sub-themes (Braun et al., 2022; Braun & Clarke, 2006). Six main steps involved in TA (Braun & Clarke, 2006) were followed: familiarization, coding, generating themes, reviewing themes, defining themes and data interpretation. Each transcript was analysed individually along with field notes taken during each focus group, anonymized, and double checked by the first author for accuracy with the original recordings. A reflexive and team-based approach was used, the core study team, (SD, KJ, KV, and AB) met every 2–4 weeks to discuss data analysis and areas for

further exploration in relation to the study aims. Themes were developed from the transcribed data, using NVivo1.6.1 (1137) software (version 1.6 2022). Data were independently reviewed, coded, and coding agreed upon by two researchers (SD, AB), as suggested by COREQ (Tong et al., 2007). Data analysis considered the transcripts from each focus group and two individual interviews, determined that thematic saturation had been achieved. This approach ensured that saturation reflected the depth and breadth of the data, rather than mere repetition (i.e., information redundancy), and supported the analytic rigour of the study. Data were also explored to identify similarities and differences across the three participant groups. Informal caregiver and therapist experiences of the FMG programme perceptions were examined in relation to the main themes arising from stroke patients, being the target population for the intervention. Direct quotations were identified to support major and sub-themes to reflect participants' perceptions (Tong et al., 2007).

Results

Following purposeful selection and subsequent efforts to contact and screen 60 stroke patients from the ARCOS-V registry, 18 (30%) declined, 21 (35%) were difficult to contact and 15 (25%) did not meet study inclusion criteria [no stroke ($n=4$); no PSF ($n=5$); no caregiver available to participate ($n=4$); stroke out of time frame ($n=2$)]. Six stroke patients (10% of those screened; 67% male, 4–9 months post-stroke) and their informal caregivers (83% female), and three therapists from the FASTER study (100% female) were recruited between September and December 2021 (Table 2). Stroke patients attended at least 50% of the online FMG sessions, with four patients (67%) attending five or six sessions. No adverse events were reported during the study.

Themes and sub-themes

Four main themes were identified, describing the experiences of stroke patients, their informal caregivers, and therapists of the online version of the FMG intervention: *Positive experiences of group membership; gaining new understanding*

Table 2. Sample characteristics.

Name	Sex	Age	Ethnicity	Months since stroke	Name	Relationship to stroke patients
Stroke patients					Informal caregivers	
Sp-1	F	57	Asian	6	Cg-1	Friend
Sp-2	M	74	NZ European	7	Cg-2	Daughter-in-law
Sp-3	F	67	NZ European	4	Cg-3	Husband
Sp-4	M	69	Māori	4	Cg-4	Daughter
Sp-5	M	45	Samoan	9	Cg-5	Wife
Sp-6	M	80	NZ European	4	Cg-6	Wife

and strategies; Navigating challenges in an online setting; and future directions. Table 3 presents each of these themes alongside nine sub-themes and a selection of representative quotes from stroke patients, their informal caregivers and/or therapists.

Theme 1 – Positive experiences of group membership

In the first theme, stroke patients shared their experiences related to being part of a group. Initial sessions provided an opportunity for stroke patients to talk about their strokes and their impact. Therapists also acknowledged the supportive environment created by the group. This theme is further discussed under the following two sub-themes.

I am not the only one

Stroke patients described a sense of normalcy and relief through sharing their experiences with other stroke patients. The group environment fostered cohesion and allowed for the normalization of post-stroke experiences, including the acknowledgement of common concerns and negative feelings related to stroke and disability. Patients felt comfortable sharing their experiences, some for the first time, and realized that others faced similar challenges, leading to a normalization of physiological and behavioural difficulties.

I think I just had self-doubts about and there's something wrong with me and now I realize it's just not something wrong with me. It's something I've got a problem. I have, but I'm not the only one, and I think that's sort of made me look at things a little bit differently. (Sp-6)

It was great meeting other people and in the same time, same boat as me ... None of my family have got any understanding but the people in the Zoom meeting did. (Sp-3)

Therapists also highlighted two key benefits of group membership for stroke patients. Firstly, being in a group allowed patients to interact with individuals at various stages of recovery, providing diverse perspectives on managing fatigue. Secondly, sharing emotional stories and coping strategies helped to normalize their experiences and conveyed the message "I am not alone."

A huge benefit to the group, some of the reasons mentioned – that people could see the progress; that others had made. People who have made progress could encourage those who were perhaps earlier in their journey and really engender a sense of hope. So, I thought it was hugely beneficial to have the different stages. (Th-3)

it was so helpful being with others who were in the same situation. Often, they felt others understanding fatigue and labelling it something quite validating, round others really got it. (Th-2)

Table 3. Themes, sub-themes, and representative quotes.

	Sub-themes	Sample quote
1. Positive experiences of group membership	1.1 I am not the only one	<p>"I have to admit I have learned a lot from it. I think have the interaction with the other people and I find now that I'm not the only one" (Sp-6)</p> <p>"It doesn't matter if you are young or old. – the reason why I say it benefit because it's good to know about what you can help with my husband" (Cg-5)</p>
	1.2 Emotional support	<p>"We had a lot of discussion about how much I came a long way like physical and mentally, and there was a great support like, so you enhance your next level" (Sp-4)</p> <p>"One lady talks about how worry about everything, worry about anything and it changed her life" (Th-3)</p>
2. Gaining new understanding and strategies	2.1 Needing knowledge	<p>"The program when it's started, started off has changed lot of things in my life. You know I have done lots of things that I have to deal with and its better balance" (Sp-4)</p> <p>"I found the ability a breath and changed the way my body was reacting to my thoughts and also to changing the thoughts itself, which help me put me to sleep. There were some good points about really found were nice and help to me" (Sp-2)</p> <p>"Now you know what to do. Not like before. It's like normally don't know anything about stroke" (Cg-5)</p> <p>"Uh, my guess from the course we it kind of brought to light and validate what the effect is after the stroke. And then the fatigue is a problem" (Cg-2)</p>
	2.2 Strategies for managing PSF	<p>"I have to walk uphill and you know exercises of breathing really helped you to get there. So, you don't tumble over. So, you don't feel so, you're not gasping for breath-up halfway walking-up a hill. And this one I was like most of these challenges. Things like that especially you know when you go for kilometres walk so breathing really helps on the longer way" (Sp-4)</p> <p>"Lot of people talk about at the end that was useful – The things that were triggering their fatigue and the things there helping over the time, and nice comparison after some weeks progress, they had made it as well" (Th-2)</p>
3. Navigating challenges in online setting	3.1 Online group sessions	<p>"I have been in the Zoom before. But this is a very old laptop, and it's a tinny laptop, it has lot of car stuff on it, hasn't looked after the laptop (laugh), so I struggled, I do struggle to use this laptop"(Sp-3)</p> <p>"I think some things are lost a bit with doing over Zoom" (Th-2)</p> <p>"I think they're looking at the screen can be quite straining, but I can certainly imagine if it's in person, that could do a solid two hours and then have a good decent break where people actually mingle and get to know with each other" (Cg-3)</p>
	3.2 Impact of PSF and other factors on participation	<p>"I had some groups whereas we changed by mutual agreement, we changed the start and finish time. Just because it fitted better for people" (Th-1)</p> <p>"I found hard to there was content on stress and anxiety and I really traditionally I've always talked about ah, anxiety being on a continuum and how it part of how it is, evolutionary usefulness and not that normal and that content in the programme</p>

(Continued)

Table 3. Continued.

	Sub-themes	Sample quote
		goes to the, with the medical or scientific definition of stress and I always found it hard to not to find it hard but noticed, not being there? to normalise and put it into, than that something that all experience, why and how to develop" (Th-3) "Now I've got into the habit of going for a while and just sort of taking a break, a small break and sitting down for a minute. And I'm doing the breathing exercises. I think that is really helping me a lot" (Sp-6)
4. Future Directions	4.1 Longer timeframe	"Maybe in a few months' time, the follow-up will catch up with other participants. Whether you know what we have taken from this program, whether how we have put it into practice" (Sp-1) "Because the improvements are so slow sometimes – I mean/guess everybody is different, and it depends upon – what happened in the stroke. So, I think a longer time is better, yeah" (Cg-1)
	4.2 Hybrid (online and in-person) sessions	"Zoom seems good as gold. It's as clear as everything ... I think it's good" (Sp-6) "I was just reflecting how Zoom sessions everybody attends I should touch worth; everybody attends every session and that was probably partly due to being in a lockdown because I am sure otherwise people life's getting away" (Th-2)
	4.3 Need for specialist skills	"Felt that she was very much part of the team. She was just another square on the box on the screen" (Sp-2) "She's aware of what you're saying and how you're saying it, and she can put the explanation across if somebody doesn't come out with it quite the way it should" (Sp-3) "It was going to be rolled-out, for example that the people running these groups might like to have a said yeah resources for people with stroke in case they encounter these kind of scenarios and the groups that can like help people get linked up" (Th-3)

Note: Th – therapist, Sp – stroke patient, Cg – caregiver.

Emotional support

Stroke patients found that being part of a group was a supportive experience that provided the opportunity to discuss and share their feelings post-stroke, such as sadness, frustration, guilt, and fear, and to learn from each other's coping strategies.

I find the program really good; be able to talk to other stroke survivors, how they feel, and I think we all go through different challenges, we all got different ways of doing things. (Sp-1)

I think sitting back and listening to other people the same situation and then sort of taking stock of what they recommended and doing it. It's made a big difference to me. (Sp-6)

Informal caregivers noted positive emotional benefits from observing the group sessions.

She's been going through all the things that have been said at the meetings, and she's sat down and thought about it. And it's all starting to make sense now. You know she can't say no to the children, you know we can't have the grandchildren, and you know, be too tired. (Cg-3)

I can see – he's feeling less guilty about taking breaks as well, because I guess he knows that – because of my stroke and I do need to make intentional effort to take breaks and have rests otherwise at the end of the day, I'll break down. You know that kind of mentality. So that is really good. And then I guess that it. It's helped with the whole acceptance with rehabbing and living within post stroke fatigue. (Cg-2)

Yeah, the reason why I say it benefits, because it's good to know about what you can help with my husband. The stroke happened to him. What I can help with, like if he needs help or he needs rest. (Cg-5)

Theme 2 – Gaining new understanding and strategies

The second theme focused on participants' experiences of gaining new understanding through the FMG intervention. Stroke patients and their informal caregivers acknowledged the need for greater knowledge about stroke and PSF, as they had limited prior education. One stroke patient's initial doubt about fatigue contributing to their situation was addressed by diaries, highlighting the value of keeping a diary. Therapists also highlighted the valuable role of patient fatigue diaries to monitor their fatigue and its triggers, and to identify helpful management strategies.

I actually wrote down day by day what I have been doing because in some days I was having rest in between things. And other days I was working right through, by recording actually what I have done enabled me ... to suddenly realise that natural actual fact, a lot of this is stroke-related. Ahh and that my intensity to be able to work at physical jobs has definitely changed. (SP-2)

A lot of people talk about [diaries] at the end that was useful where to see them, their fatigue was. The things that were triggering their fatigue and the things they're helping over the time, and nice comparison after some weeks progress. (Th-2)

This theme regarding new understanding and strategies is further discussed under the following two sub-themes.

Needing knowledge

Stroke patients noted a lack of prior knowledge about stroke and PSF before the intervention. Some weren't aware that stroke could occur at any age in life, nor that stroke could occur in younger people and be followed by long-lasting fatigue.

I think this programme is really good the knowledge that we learn from it. There are things that I never learn like I said before I always thought the only people 60 and over have the stroke. (Sp-5)

I think that after attending this course, I realized that you know, uh, post stroke fatigue can last longer from the initial insult. (Sp-2)

Informal caregivers also mentioned having limited knowledge of stroke and PSF prior to the intervention. New knowledge helped caregivers to understand the symptoms of PSF and develop a deeper understanding of stroke and its effects on the lives of their loved ones.

It's like normally [I] don't know anything about stroke. (Cg-5)

for me, it validates some of the warning signs that I kind of knew. His warning signs that I thought that it could be this, but I wasn't sure. But after attending this course and listening, listening to other people's experiences, it kind of reconfirmed that. Oh, yeah, actually it is. Maybe because of the stroke and then this. This is how my Papa behave, when he is overtired. (Cg-2)

Therapists also emphasized the importance of stroke patients and their informal caregivers attending sessions together to enhance their understanding of stroke and PSF.

It was really helpful to people[caregivers] to have there because, well it seems that we know like both got the same information. – the feedback from the clients was helpful because I didn't have to remember everything and they didn't have to try and tell people at home how they wanted things to be different. So, I found it really really helpful. (Th-3)

Therapists found the cognitive behavioural model of mood/fatigue, that was presented as part of the intervention, particularly helpful for explaining relationships between mood, thoughts and fatigue. However, therapists also acknowledged that some stroke patients found it challenging to incorporate this complex model into their own lives.

[At the] end of the programme we were asking people to have a discussion around the most benefit and so understanding fatigue was one and lot of people, the model of emotion that was the real benefit for them. (Th-3)

about [the] model, I had two clients for whom it was an incredibly powerful tool, but in a way, it made them realise that was quite distressing for them. It made them realise some quite difficult truths – about their own life, and their own behavior. (Th-1)

Strategies for managing PSF

Stroke patients and informal caregivers found education on strategies to manage PSF beneficial. Sleep hygiene, breathing exercises, energy conservation strategies, and using a diary were highlighted as helpful.

Now I've got into the habit of going for a while and just sort of taking a break, a small break and sitting down for a minute. And I'm doing the breathing exercises ... I think that is really helping me a lot and then I'll go back and work a bit longer and when I feel tired, I think that's it. I've had enough now so stop ... I'm feeling so much better every day for doing that, and I think that's been the big plus for me. (Sp-6)

I find the breathing exercise helped me to stay calm and dairy helped me too. Did give a good picture of how I am before all this happened. It does help me to manage my fatigue. (Sp-1)

I thoroughly enjoyed the sleep one and the resting and the breathing. I think – those were highlighted and brought to light a number of issues for me and it was fine and I've rehashed. (Sp-2)

Theme 3 – Navigating challenges in online setting

The third theme focused on challenges associated with delivering the FMG intervention online and the impact of PSF on participation. As noted by therapists, some stroke patients expressed hesitation in using unfamiliar technology to take part in the FMG and sharing their experiences in an online group setting. Therapists also acknowledged challenges working online with stroke patients at different stages of recovery and varying levels of fatigue. This theme regarding challenges is discussed under the following two sub-themes.

Online group sessions

Some stroke patients and informal caregivers had limited prior exposure to using computers and installing and using Zoom.

Some people were older and did not feel comfortable with the technology or didn't have access to Zoom. Or someone likes to support them to get access to Zoom for those times it wasn't feasible. (Th-1)

My first Zoom. There I never been on Zoom before. (Sp-5)

I get stressed really easily now that like for instance, this morning when we couldn't connect onto the Zoom meeting, I just thought, I'm just gonna walk away. I can't be bothered with this. But persevering got through it. (Sp-3)

Despite technological challenges reported by stroke patients and their informal caregivers, therapists noted that the high rates of attendance at the online sessions reflected the possible roles of COVID-19 and no need to travel.

I was just reflecting how Zoom sessions everybody attends I should touch worth, everybody attends every session and that was probably partly due to being in a lockdown, because I am sure otherwise people life's getting away.(Th-2)

... travel time, and other comorbid health difficulties was the primary thing that caused people to drop-out from the FMG sessions delivered in-person in the FASTER study. (Th-1)

Impact of PSF and other factors on participation

Some stroke patients found attending groups online was fatiguing. One stroke patient, experiencing significant fatigue during an online group session, noted looking at a computer screen for a long time was tiring. Informal caregivers also acknowledged the role of PSF and mentioned the importance of regular breaks.

I can spend up to 45 minutes to hour is a maximum. My brain just switches off. I get really, really tired, and especially because I been not well. If we have a break halfway then it will be good. (Sp-1)

I do find Zoom is a bit challenging because of the computer screen ... I get tired. (Sp-1)

I think having a break was really important, especially you know a break halfway up. I know for the first 3 sessions, – found it really, really tiring and come because she had to do so many Zoom meetings like 3 days in a row. She did find this one quite tiring. (Cg-1)

Therapists also acknowledged challenges working online with stroke patients at different stages of recovery and varying levels of fatigue.

It's hard to have some people at different stages of fatigue in the group. I want to come back to that. Because that was something I was looking at running groups. That was the most concerning for me. (Th-1)

I had a few people in the group who were, yeah I guess really hard on themselves. – and blaming of themselves, was for having a stroke and not all of the participants exactly the same. (Th-2)

I got fatigue but in a bit in denial about that prior to it, but I have got associated heart disease and I we've be quite unwell with that as well. So, I don't know if it's a combination of stroke and heart disease or just a stroke. (Sp-3)

Relatedly, therapists felt that younger stroke patients had issues specific to their stage of life (e.g., work, and finances) and may have benefitted more from one-on-one sessions, especially when it came to discussing private information and other forms of support.

A quite a few young people had stroke and had implications their work, then rent and all those financial things ... (Th-3)

The young stroke participants (under 40) with young families, and PSF struggled with financial issues ... linking these people-up with Stroke Foundation things like that ... (Th-3)

Theme 4 – Future directions

The fourth theme identified concerned the future direction of the FMG intervention. In addition to positive comments about the intervention, participants offered a range of suggestions.

I think the system was really good. I think the program is a really, really informative and really helpful. I'd like to thank everybody and thank everyone for sharing this on program. I enjoyed the program 100 percent. (SP-2)

Three sub-themes were identified in relation to the future delivery of FMG: longer timeframe; hybrid (online and in-person) sessions, and specialist skills.

Longer timeframe

While the intervention provided weekly sessions for 6 weeks, stroke patients, informal caregivers and therapists recommended extending the length of the intervention to cover a longer period of time and provide on-going support.

I think, more time just to follow up and see what everybody's doing ... that sounds good ... I think, three months or six months or something like that. yeah, I think not a short time. A longer time is better. (Sp-5)

Because the improvements are so slow sometimes. I mean, I guess everybody is different and it depends upon the you know what happened in the stroke. So, I think a longer time is better, yeah? I think that could be a really good idea. (Cg-5)

Some people – Yeah, they're wanting to process the content and some people might take longer in that and in doing so. (Th-3)

Hybrid (online and in-person) sessions

Stroke patients and therapists appreciated benefits of online delivery in terms of convenience and cost-effectiveness, eliminating the need for transportation and formal attire. Additionally, stroke patients felt that online sessions were beneficial for individuals with comorbidities or those living in rural areas. Participants also emphasized a preference for and advantages of in-person sessions.

I think there are definitely, some advantages to doing face to face, but I am thinking about harder to reach places, where you know the closest places, clinic might be hour or more away. (Th-2)

... I would prefer face-to-face and Zoom. (Sp-6)

Now in these days and age with what we've got to put up with at the moment with this pandemic, I think Zoom is perfect. As I said, this is my very first ever session that I've ever done on Zoom. – I think, it's fabulous. But I do like to actually go to a meeting sometimes and sit around; you know it's quite nice, you get more of an interaction between everybody else. (Cg-6)

Need for specialist skills

Therapists highlighted the value of specific therapeutic skills, which one therapist felt were specific to psychologists. More broadly, therapists noted the importance of providing individuals with the space to discuss the impact of their stroke, recognizing their identities beyond being a person with stroke,

and the importance of creating a comfortable and connected environment among group members.

The future of this intervention [should] continue to involve psychologist facilitating, I think their skills that are specialist to psychologist ... it could be quite a different programme if other professionals were running [it]. (Th-2)

What I understand, Psychologist or whatever flavour happen to be, – the therapeutic skills bring a group together. Once that comes quite naturally to us. So, you know skills like active listening, being alert to purification, allow people to have a voice and work doing before and after people feel just to comfortable and therapy space which they ensuring. (Th-1)

First couple of sessions also allow for space for participants to talk about the stroke and talk about the impact of the stroke. And also talk about who they are being outside the identity of having the stroke, so have that conversation of connecting. (Th-3)

Therapists also suggested further use of their skills by incorporating a grieving model, to help stroke patients come to terms with their loss and grief, and to accept changes in their lives post-stroke. Additionally, therapists recommended integrating established mindfulness tools to cultivate self-kindness, self-understanding, control, and the ability to let go, facilitating progress in their journey.

This is slightly off-topic, one they have been alerted to in our discussions already. I was just thinking about how there's process of acceptance that happens in the group through that normalization of fatigue that being around others who have had the stroke. And I don't yeah, I know one participant reflected at the end like that was like the grief around having a stroke and that whether they needed to be more space or a different space to be able to process some of that. But how when I look at the end, I could think there's one person, particularly think like what he got out the programme with acceptance and enable him to move forward and make over the changes to that over to help him manage his fatigue, yeah. (Th-2)

There is a quite established model for acceptance post-stroke a bit process that people go through, and it might be helpful to embed that somehow into the content, so that is suggested can be implicit that we're normalizing – process of grief that you will go through your own stuff, better, best or worse. And just allow people to move through that, so that they were not always told that they were still grieving. Got a few expectations that have been exactly the same as they were before, they are struggling. Most people they get there that like, but for some were they don't. They're still fighting. (Th-1)

The people found the relaxation session and the breathing really helpful, and, often hadn't been exposed to that before, ah and I, it got me thinking about how you know there's a lot of evidence of mindfulness now? So, I don't know whether that could be incorporated, any differently in the programme or whether it should be. (Th-2)

Stroke patients also emphasized the knowledge and skills of therapists delivering the intervention, including understanding the specific needs of patients with stroke.

She really came over much as one of the team. I didn't really think of her as a teacher or a moderator, or controller ... She was respectful for everybody that was here, and she was understanding and she actually had answers to questions or certainly was able to explain situations that other people were experiencing, so I don't I think it needed to be a medical person. (Sp-2)

Discussion

This qualitative study captured experiences of stroke patients, their informal caregivers, and therapists regarding an online version of a group-based PSF fatigue management intervention. Whilst the main FASTER study did not show a statistically significant effect of FMG treatment (Jones et al., 2025), qualitative insights from the current study indicate participant preference for the FMG intervention, suggesting its potential benefit with targeted refinements. This highlights how qualitative research components of randomized controlled trials can provide valuable insights for both the full trial and future research studies. Additionally, a similar qualitative study on managing PSF explored the experiences of stroke survivors and carers in an outpatient rehabilitation setting using individualized programmes. The findings highlighted the need for developing tailored management interventions and optimal rehabilitation strategies suited to different cultural groups (Bicknell et al., 2022). Furthermore, another study explored clinicians' experiences managing PSF and identified common fatigue management approaches across various conditions, emphasizing the importance of clinicians' own knowledge and shared perspectives across professional groups in shaping treatment strategies (Drummond et al., 2022). Therefore, the current research incorporated a structured, group-based intervention and engaged all three key participant groups: stroke participants, therapists, and caregivers, enhancing its contribution to the overall findings. The study findings revealed four key themes.

The first theme of "Positive experiences of group membership" referred to the benefits of connecting with others to normalize and share experiences within a group setting. Being part of a group appeared to foster a sense of connection among stroke patients and contributed to the emotional well-being of stroke patients and their informal caregivers. These findings align with evidence suggesting that participation in small group sessions, informed by CBT principles, facilitates interpersonal relationships and cohesiveness, while also providing opportunities for positive reinforcement and reducing social isolation commonly experienced by stroke patients (Vocisano et al., 2004; Whitfield, 2010).

The second theme, "Gaining new understanding and strategies," revealed that stroke patients, their informal caregivers, and therapists valued the educational content of the intervention which provided better understanding of stroke and helpful strategies for managing PSF. The use of daily fatigue diaries to track and manage PSF, as well as stress management techniques like relaxation, sleep hygiene and breathing exercises, were valued by stroke

patients in the current study. These strategies align with the principles of treatment for psychological therapy for anxiety disorders (Clarke et al., 2012; Thimm & Antonsen, 2014; Whitfield, 2010). Consistent with existing literature (Braun et al., 2022; Vocisano et al., 2004; Whitfield, 2010), education regarding energy conservation and restoration were appreciated by participants and align with recommendations to provide education for reducing PSF, particularly in the subacute phase of rehabilitation (Vocisano et al., 2004; Whitfield, 2010). Caregivers in the current study acknowledged their limited understanding of stroke and identified gaining new validating information as important. Other studies have identified the importance of gaining understanding and validating information as vital for caregivers (Mou et al., 2022; Thomas et al., 2019).

The third theme, "Navigating challenges in online setting," highlighted the initial technological difficulties faced by stroke patients; mainly accessing and navigating new technology. Due to limited prior exposure, learning to use new technology (Zoom) and participating in online group sessions was a considerable challenge for many stroke patients and their informal caregivers. An additional challenge, raised by therapists, related to facilitating groups of stroke patients with different comorbidities, levels of fatigue and capacity to participate for the duration of each session. Therapists felt that some stroke patients may have benefited from one-on-one sessions, and/or more regular breaks during sessions. Relatedly, stroke patients reported difficulty concentrating for more than 30 min during online sessions and suggested incorporating more frequent breaks. Similar challenges have been reported in other studies of group interventions for stroke patients (Chen et al., 2015; Purvis et al., 2022; Turner et al., 2022).

Within the fourth theme, "Future Directions," stroke patients and their informal caregivers acknowledged the convenience, cost-effectiveness, timeliness and social connections (particularly during the COVID-19 pandemic) offered by online sessions, eliminating the need for transportation and formal attire. Additionally, stroke patients felt that online sessions were beneficial for individuals with comorbidities or those living in rural areas. However, stroke patients ultimately recommended a hybrid approach combining in-person and online sessions. They believed this format would offer greater opportunities for interactions among group members, while also providing flexibility and accessibility to continue to deliver group sessions when barriers impact in-person delivery (e.g., COVID-19). Stroke patients and therapists also suggested that the length of the intervention be extended to cover a longer period (e.g., 3–6 months duration) to provide extended support and education and allow participants more time to absorb new learning and effectively apply new strategies to manage PSF, with the option of one-to-one sessions to provide an opportunity to discuss any sensitive information. It was also clear that the skillset of therapists played a crucial role in facilitating the intervention for stroke patients, recognizing the importance of the patient–therapist relationship. This is crucial in stroke care, as post-stroke symptoms often include emotional distress (McCurley et al., 2019). While clinical

psychologists can provide specialized care and skills to address these emotional needs (Perna et al., 2020), it is reasonable to consider that similar skill sets could be offered by other health professionals with sufficient training. While challenges to participating in, and delivering the intervention online were identified, overall participants valued the opportunity to connect with others, to better understand and accept PSF, and new knowledge about its management.

Strengths and limitations

This study's strengths included its rigorous screening criteria for PSF, ensuring a well-defined participant group, and its purposive sampling approach, which enhanced diversity and allowed for a comprehensive exploration of experiences from stroke patient, informal caregiver, and therapist perspectives. The study was limited by the small number ($n = 3$) of participating therapists. While this could have been expanded for greater benefit, the participating therapists represented 60% of those who participated in the main FASTER study (Jones et al., 2025). It is also important to acknowledge that some participants did not attend all FMG sessions, potentially impacting the consistency of data collection and findings. Therefore, appraisals of the intervention are limited to experiences of those sessions attended. Additionally, while the majority of FMG sessions in the main FASTER trial were delivered in-person (Jones et al., 2025), this study examined the intervention in an online format due to COVID-19 restrictions. The extent to which this change in delivery mode influenced the intervention's effectiveness remains unclear.

Conclusions

Study findings suggest that the online delivery of the group-based FMG intervention offered valuable insights for stroke patients and their informal caregivers. Benefits included fostering a sense of belonging or normalcy, enhancing understanding of PSF, and offering effective management strategies. Caregivers found their involvement as observers particularly helpful in gaining a better understanding of the impacts of PSF on family members and its management. Further research, ideally including co-design with stroke rehabilitation providers, patients and their families, is needed to refine and deliver a hybrid approach (combining in-person and online sessions) to better support stroke patients and their families manage the impacts of PSF.

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Author contributions

All the authors made substantial contributions to editing and revising of the manuscript. KJ, SD and KV were responsible for the study design. SD drafted the initial manuscript. SD and AB were responsible for the qualitative analysis. All authors approved the final manuscript.

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