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Experiences of acquired brain injury survivors participating in online and hybrid performance arts programmes: an ethnographic study

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ABSTRACT

Background: Performance arts can benefit people with acquired brain injury (ABI). This study explored the online delivery during COVID-19 restrictions, of a performance art intervention through the experiences of participants, artists and facilitators.

Methods: Two community-based programmes were delivered. Online ethnographic observations and semi-structured interviews with participants, artists and facilitators were completed.

Results: The programmes benefited participants by addressing loneliness and isolation; building confidence through peer support; improving physical limitations through movement; improving communication through music and vocal work; and using poetry, visual arts, metaphor and performance to make sense of participants' experiences. Participants had mixed experiences of participation, but it was an acceptable alternative to in-person arts interventions for those who overcame digital challenges.

Conclusions: ABI survivors can engage in online performance art programmes and find participation valuable for their health, well-being, and recovery. More work is needed to explore the generalisability of these findings, especially given digital poverty.

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Stroke; brain injury; online; performance; participation

Background

Acquired brain injury (ABI) is a broad term for any injury to the brain sustained since birth, including traumatic brain injury and stroke (Jolliffe et al., 2018). Individuals with ABI can experience physical impairments and less obvious "hidden" disabilities relating to cognitive, emotional, behavioural or communication impairments. ABI can affect any aspect of a person's functioning, and individuals commonly experience a loss of confidence, autonomy and

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independence (Headway, 2009). Many people with ABI experience mental health issues such as anxiety and depression (Ayerbe et al., 2013). Stroke survivors have a 50% chance of experiencing depression in the first 5 years post-stroke and a high incidence of anxiety and depression compared with the general population, with a rise in post-stroke anxiety during the COVID-19 pandemic (Ahmed et al., 2020; Ayerbe et al., 2013). Individuals with a hidden disability can often have unmet needs in the long term, associated with lower life satisfaction and worse medical health and psychological well-being (Heinemann et al., 2002). A 2019 survey by the UK Stroke Association revealed that 50% of stroke survivors and 85% of carers felt they needed increased support (Stroke Association, n.d.). Studies have also shown that in the longer term, individuals with ABI are more likely to experience social isolation and a reduction in social networks (Northcott et al., 2016). There were 356,699 UK admissions to hospital with ABI in 2019–20, an increase of 12% since 2005–6 (Headway, n.d..). The prevalence of ABI is high, and there is clear evidence of the need for more rehabilitation and support after discharge from the hospital to address social, emotional and physical needs (Headway, 2022; Konrad et al., 2011).

Interventions to address social isolation and emotional wellbeing have shown the benefits of engagement in leisure activities, including music and dance. There is evidence of a relationship between engagement in leisure activities and the prevention and management of mental and physical health conditions (Fancourt & Finn, 2019). This relationship is explained by a range of causal mechanisms encompassing psychological, biological, social and behavioural processes (Fancourt et al., 2021). For example, listening to music, making music, singing, and dancing have been shown to influence mood, emotions, and communication ability and are strongly associated with memory reminiscence and increased activity in people recovering from a stroke (Baylan et al., 2018; Schlaug et al., 2010). Post-stroke dance programmes have additionally shown a range of benefits, including self-reported improvements in walking and balance (Patterson, Wong, Prout, et al., 2018; Patterson, Wong, Nguyen, et al., 2018 Jarrett, 2018).

Cultural and artistic activities for people with ABI during the pandemic

The COVID-19 pandemic and subsequent lockdowns intensified the challenges experienced by individuals with complex conditions, with reduced access to rehabilitation and increased isolation and loneliness affecting many people (Gronewold & Hermann, 2021). The UK charity Headway found that 57% of people who sustained their brain injury within the past two years reported that COVID-19 has negatively impacted their access to specialist treatment, while 64% of those living with the long-term effects of brain injury reported a deterioration in their mental health due to COVID-19 restrictions (Graham et al., 2021). Post-stroke anxiety showed a noticeable peak during the pandemic, relating significantly to social isolation and lack of rehabilitation (Ahmed et al., 2020). Thus the COVID-19 pandemic raised calls for research targeting specific groups to understand their experiences of this time and explore the feasibility and impact of creative measures and activities to address their unmet needs.

Additionally, the COVID-19 pandemic prompted the need for cultural and artistic activities to be re-designed and delivered online. The online delivery of performance arts programmes for people recovering from ABI has not been researched previously. Questions arose about whether people with ABI could access and engage in online sessions, whether the benefits of such programmes could still be achieved when delivered online,

and whether it would be possible to build a sense of connection and community between online participants. The benefits of engagement opportunities and "collective efficacy" for people living with long-term conditions have been highlighted previously (Vassilev et al., 2019). Prior to the current study, it was not known whether this could be achieved through online groups. Future practice could be usefully informed by gaining insights into new ways of creating personal communities and collective efficacy for people with limited ability to attend in-person events. Learning about the barriers and facilitators to online delivery of arts for health programmes would help inform future delivery.

The "Brain Waves" research project was created as part of the COVID-19 pandemic response to address this research gap. A protocol paper for the study has been published separately (Estevao et al., 2022). The aim was to explore the experiences of individuals with ABI accessing performance arts programmes online and the experiences of artists and facilitators delivering the intervention. The programmes were developed and overseen by Rosetta Life, a UK based charity with an established history of providing face-to-face performance arts programmes to build confidence in people living with ABI. The online interventions used in the study were developed from the existing in-person Brain Odysseys intervention delivered by Rosetta Life (see rosettalife.org).

Research methods

Research approach and methodology

The methodological design of this qualitative study is based on Interpretative Phenomenological Analysis (IPA) and ethnographic methods (observations and interviews). Ethnographic methods were used to investigate social interactions, behaviours, experiences and perceptions (Reeves et al., 2008). These methods included observing online sessions, writing ethnographic fieldnotes based on these observations, and conducting semi-structured interviews. Approximately 48 hours of observation were undertaken.

IPA informed data collection and analysis, leading to a detailed exploration and analysis of participants' experiences, meaning and sense-making (Smith 2011). Interviews and observations sought to explore the experiences of delivering or participating in a new online iteration of the more established in-person performing arts programme.

Research aim and objectives

Aim: To understand the implementation and experiences of an online community-based performance arts programme for people with ABI.

Objectives:

(1) To understand the experiences, benefits, and opportunities of participation in online performance arts programmes for participants living with ABI.
(2) To study the mechanisms of delivery and interactions between participants, artists and facilitators during online delivery and the concept of creating a personal "community" in the new context of an online group.
(3) To evaluate to what extent the online programme is acceptable, appropriate, and feasible.

Recruitment

Participants

Brain Injury participants for the online performance arts workshops were recruited by signposting in community centres, care homes and the engagement offered through the presentations, screenings and taster sessions delivered by Rosetta Life. Due to the COVID-19 pandemic, most of the recruitment was done online. Rosetta Life contacted brain injury survivor groups in their network and offered the groups a taster session. Following the taster session, if people expressed an interest, Rosetta Life sent out flyers with their email address and website and invite them to be part of the research project by sending the Participant Information Summary (PIS) and Informed Consent Form (ICF).

Stakeholders

Wider stakeholders were recruited from the network of people involved in the referral, delivery or supporting of the programme. In addition, the participants from past programmes that became ambassadors referred friends, peers and people they knew who were living with an acquired brain injury.

Finally, there were self-referrals from people aware of the programme, in which case they were then invited to join the programme, after being sent the PIS and ICF.

For artist recruitment, Rosetta Life sent out PIS and ICFs to artists who they have worked with in previous brain injury programmes, and invited them to be part of the research.

Participants

In Rosetta Life's delivery model, participants include "ambassadors" who have completed previous programmes and join with the expectation that they act as role models for new participants.

Each programme was devised and produced by two artists (experts in delivering music and dance workshops and composing music with community groups), and the London programme also had an additional composer. Each programme was supported by at least one facilitator who worked behind the scenes to coordinate sessions, invite participants, and provide them with technical support, e.g. to connect online and use Zoom. There were 1–3 facilitators supporting each session (with the need for support generally reducing as participants became familiar with joining online).

All participants, artists and facilitators in the programmes were invited to participate in an interview. Pseudonyms are used for participants/carers, and artists and facilitators are referred to by their roles. In London, there were 22 programme participants, including 6 ambassadors, and in Donegal, there were 8 programme participants. See Table 1 for interview participant data.

Data collection

Ethnographic observations of online and face-to-face sessions took place online via Zoom. Written fieldnotes captured the researchers' observations and experiences of the sessions, including interactions between participants and facilitators, observations of verbal and

Table 1. Interview participants.

Participants (n)	Age (mean years, SD)	Gender (Male, Female, %)	Type of ABI (Stroke, ABI, %)	Time since ABI (mean years, SD)
London (13)	64 (11.8)	Male (53.8%)	Stroke (100%)	5 (4.7)
Donegal (8)	63 (16.7)	Male (50%)	Stroke (100%)	6 (2.3)

non-verbal responses, and reflections on the barriers and facilitators to effective online delivery. Example fieldnotes from each site are included as supplementary files (S1).

Interviews took place via Zoom, telephone or in person and were audio-recorded and transcribed before analysis. Interviews for each site took place after the programme of workshops at that site had ended. Although a topic guide was followed, the interviewer's experience as a participant-observer in sessions led to richer discussions than would have been possible with the use of interviews alone, as participants could refer back to specific moments or situations the interviewer had witnessed. Interviews ranged from 15–89 minutes, with a mean of 45 minutes. Summary notes were made to record observations during or after the interviews. All participants gave informed consent and could opt out of any research activities and/or withdraw from research activities without providing a reason. Interviews were transcribed verbatim.

One author (ET) was the main researcher, and a second researcher (FJ) observed a selection of sessions and met with ET every week to discuss observations and review fieldnotes. The wider research team met regularly to discuss the project, including the planning and delivery of the intervention.

Data analysis

Examples of data analysis are included in supplementary files (S2: Data Analysis). Analysis of interview data began at the micro-level with descriptive line-by-line coding of the experiences voiced by participants, identifying things that mattered to the participants (objects of concern) and the meaning of those things to participants (experiential claims) (Larkin et al., 2006). These annotations were collated for each participant and then refined into "meaning units". Patterns were sought in the meaning units across all the interview data. These were then developed into themes. ET and FJ did the coding, including double-coding a selection and reviewing all coded transcripts for quality control.

When writing fieldnotes, key observations from each session were summarised and added to a table for an overview across the sessions. The researchers re-read the summaries, fieldnotes and reflections throughout the data analysis process and made further reflective notes. This aim was to enhance reflexivity, keep the researchers' experiences distinct from those of the participants, and make sense of emerging patterns and meanings. Preliminary findings were shared with participants in London via an online presentation and discussion and in Donegal via a written report. This "member checking" allowed participants to verify whether findings reflected their experiences.

Intervention

Brain Waves programmes sought to achieve the same aims as their face-to-face predecessors: to enable each participant to use performance arts to explore and accept their changed

identity as an ABI survivor. Through gradually exploring a performative self, and being witnessed, heard and understood, it is anticipated that people can test out an acceptance of life after ABI. Both sessions involved sharing stories, leading to the co-creation of music and movement culminating in a final piece. As well as participating in online guided movement and music, metaphors and themes were used to stimulate creativity, and participants shared their drawings, poems, photographs and dances via WhatsApp between sessions.

Programme 1: London

This 12-week online community-based performance arts programme took place between May – September 2021. It was facilitated by two artists and two ambassadors together in a studio, streaming a webcast to participants (including ambassadors) who joined via Zoom.

Programme 2: Donegal

The Donegal sessions took place from November 2021 to March 2022, during which Covid restrictions began to ease in Ireland. The first three sessions were delivered online, with all artists, facilitators and participants joining individually via Zoom. When it became possible for participants to meet in person in a dance studio, they opted to do so, and the researcher continued to join via Zoom. After the first 7 sessions, there was an intensive period of three full days for devising and rehearsing the performance. At this point, some Zoom participation was introduced as an option at the request of participants who could not attend all full days.

Results

Some key differences between the London and Donegal programmes are noted in Table 2 and Table 3, and provide context for the overall findings.

The key findings developed from the analysis have been categorised as follows: 1) A critical need to address loneliness and isolation; 2) What people valued; 3) Barriers and facilitators to online delivery; 4) Support and resources needed.

1) A critical need to address loneliness and isolation

Whilst the Donegal participants (whose strokes had been less recent) felt their experience of Covid lockdowns was challenging in a similar way to the general population, for the London participants, there was a more extreme level of distress regarding the Covid restrictions. Those who had experienced a stroke during lockdown were particularly affected as they could not have visitors in the hospital or when they went home, compounding the shock of their new and sudden disabilities.

Table 2. Artists and facilitator characteristics.

Artists and facilitators (n)	Age (mean years, SD)	Gender (Male, Female, %)	Role (Artist, Facilitator, %)
London (4)	58 (11.6)	Female (60%)	Artist (60%)
Donegal (3)	48 (5.8)	Female (66.7%)	Artist (66.7%)

Table 3. Models of delivery and key differences between London and Donegal projects.

London	Donegal
Delivered May – September 2021.	Delivered November 2021 to March 2022 (when Covid restrictions began to ease in Ireland).
Two artists and two ambassadors live streamed webcasts from a studio to participants who joined via Zoom.	Hybrid of Zoom and face-to-face sessions.
Participants had a range of ABIs, including stroke; some had been acquired very recently (including during the strictest Covid restrictions in 2020), while others were longer term.	Participants were all stroke survivors and were between 3- and 24-years post-stroke.
Some participants felt able to attend a face-to-face group, and others did not. Some would be able to use public transport, others would use cars, and many would need assistance with the journey.	All depended on cars to travel to a face-to-face group, but all were able to manage this.
All participants were able to connect online – broadband was not an obstacle to participation.	Broadband challenges in rural areas were sometimes insurmountable, despite considerable efforts to support people participating online.
Covid restrictions for those with recent strokes led to severe loneliness and isolation.	Participants described that Covid restrictions were challenging in the same way as for the general population.
Participants had a wide range of functional limitations and impairments, including mobility difficulties, arm weakness, communication difficulties (aphasia) and cognitive challenges (e.g. memory and thinking).	All participants had a high level of functional independence and were fully mobile. They were most concerned about difficulties with their memories, fatigue and confidence.
Sessions were delivered entirely via Zoom.	Combination of zoom sessions and face-to face-sessions.
The final piece was a video with contributions from all participants.	The final piece was a live performance.

> My carer could come up, and the physio, occasionally, but all my other people could only stand at the door. No one could have, and I felt [. . .] when you're emotionally sort of raddled and you don't feel comfortable in self, lots of things come to be, [. . .] I'm in my head, I mean (Elvis, London)

> when I had the stroke my future was like a blank. [. . .] I felt I didn't have a future, you know. [. . .] And in a way having that [Brain Waves programme] gave me something to look forward to and my future didn't feel that blank [. . .] That programme was just something that I did for me and I felt that was important. (Gwen, London)

2) What people valued: meeting and mixing, moving and making

All sessions included some physical exercises, movement or dance and some vocal exercises and singing. Small group discussions (using "breakout rooms" on Zoom) were used to explore topics and generate ideas that could contribute to the final creative piece. Participants were encouraged to explore the themes independently by drawing, taking photographs, writing, or dancing between sessions and shared these on their WhatsApp group. The London group used the metaphor of a spiral as a motif representing the "forwards and backwards" nature of recovery. The Donegal group used nature and the changing seasons as their creative theme.

Most participants had not known what to expect and joined the programme to take an opportunity to interact rather than because of a particular interest in performance arts.

> I didn't really have any expectations [. . .] but I've really enjoyed the meeting up and I've done it every week so [. . .] The people that I'm meeting with are very similar to me, in lots of different ways though, but we're still similar [. . .] I just felt like I'd lost myself and I've, I feel that

> when I'm involved with meetings with other people that it's bringing me back a bit … and I enjoyed the regularity of the things, knowing that I had weekly meetings coming up. (Jade, London)

All participants talked about the importance of being in a group with people who had experienced an ABI.

> I realised during the experience that being lonely and being isolated is very challenging you know, then coming up to a mix up with people, I know we are doing it through Zoom but you see people, you talk and you laugh […] so what I achieve is mixing up with people, talking, I feel that I'm not alone. (Precious, London)

Even online, the experience of participating was described as "joyful" and although people's challenges and disabilities varied, they were unified by their shared experience of having a stroke or brain injury. People spoke of gaining confidence by seeing what others could do.

> I note with very interest that people that were just gently moving their limbs, with real guidance by the tutors. And I, so what I started to do, I started to copycat what they were doing. […] And also, seeing the others do it, so that actively encouraged I as an individual to take part (Elvis, London)

Additionally, participants spoke positively of their experiences engaging in the movement, music and discussions. One participant with aphasia (severe difficult speaking) expressed that the groups had helped her communication to improve and she expressed herself through dance:

> "Before I don't even spoke anything, at all, I don't even say any, no […] but now I can say yes, like uh-huh. […] They know when I do this, [dancing] bam-bam-bam, that's it". [laughing] (Margaret, London)

The range of benefits participants experienced corresponded with the range of difficulties they had been experiencing.

> My left leg always, always, it's always heavy. So after doing like the exercises, I'm relieved, I'm relieved a little from the same. My fingers, as you can see, is always heavy, my right arm. After doing the exercises, I'm relieved, it moves my whole body … I mean, the movement is fantastic […] My joy is this Thursday exercise is helping me. I want to get back to my very self. (Mary, London)

Some participants valued experimenting with creative writing, photography and drawing. Some particularly identified with the "Spiral" metaphor, and others did not understand this but "went with it". The following quote shows the importance of the metaphor to one participant who valued creating her own spiral dance:

> The Spiral story is always reflecting in my memory. Because when I first look back, I look back, it shows me, makes me to think back on the day that things happened in the church. That falling to the ground suddenly […] When I looked down, I remembered only on the cart and being carried to the hospitals … But when I look up, I look up to the future […] That Spiral story taught me those lessons. […] It makes me to reflect how I started, where I stood now and where I'm going […] my dancing tells me about my past, my present and my future. (Mary, London)

Donegal participants (who had mostly been living with stroke for longer than the London group and were physically and functionally very able) were more likely to talk about the benefits of being able to process their experiences and build confidence. Many expressed that their participation had addressed confidence issues they had lived with for years since their ABIs. The following quote was from a participant who had her stroke 6 years previously.

> "I would never have dreamed of standing up and speaking in front of anybody or ever sharing what happened to me with anyone, like I would never have spoken with anyone about that I had a stroke [. . .] and now I'm able to say I had a stroke and 'I am a stroke survivor', which is just great." (Baba, Donegal)

3) Barriers and facilitators to online delivery: making connections

All participants said they had found out about the opportunity to participate in Brain Waves through their engagement with other support groups and charities, which had also been instrumental in enabling some of the participants to participate online by providing laptops, tablets or smartphones and, in some cases offering training sessions on how to do them. The importance of such support networks was evident and raised questions about people who are not engaged within these systems and therefore miss out on opportunities and support.

> If I hadn't had a key worker, and a lot of people don't, I wouldn't have known about [. . .] I wouldn't have known about the meeting, I wouldn't have gone up and I wouldn't have met all these, [. . .] whether it's online or whether it's a meeting face-to-face and it's, you know, I think that whole networking and stuff is a big thing, it's a huge thing. (Faye, Donegal)

Some practical barriers were overcome thanks to the voluntary groups and charities who provided devices or training, but the lack of internet connection in some areas of Ireland proved to be the most challenging obstacle to engagement. There was frustration when people tried to speak but froze on screen, making it more challenging to have informal chats within the group.

In both programmes, some participants appreciated not having to travel to a face-to-face session. For some, a travel requirement would have made it impossible to attend either because of their physical disability, emotional issues or lack of confidence. Others would have depended on someone else to assist with the journey.

London participants felt that online was a good alternative when meeting in person was not possible. Most Donegal participants were less positive about the online experience and found themselves distracted by the tasks that needed doing at home.

> I would be on Zoom but I had to get outside because there's flowers to be planted, the grass to be cut and a bit of painting to be done, and I found that it was long. An hour might have done. (John, Donegal)

In contrast, for many London participants, the online groups had been a lifeline when they were deprived of other activities and social connections.

> It was much better than being me and my wife, because once the carer stopped there was just the two of us, and there is the TV. You don't interact with TV but being online with others doing the same thing it was sort of more widening of, you know, giving an impression of being with some other people. (Ernest, London)

Participants with communication difficulties were able to engage in and enjoy the online groups. Philip, who had severe communication difficulties, was interviewed with his wife Rose, who could support his communication. Philip expressed finding the groups joyful and special and enjoying the group atmosphere.

The need for support from a partner was also raised by Patrick, and he also found individual sessions important in enabling him to manage technology more independently.

> "My wife and carer has got so much on, I wanted to try and do these things independently [. . .] I was at the point of sort of saying, 'Well, I'll step out because I don't want to be involved if it's going to add to Jan's burden'. And so they were, that was kind of what the one-on-one session was about, was trying to solve for that." (Patrick, London)

We were curious about whether it would be possible for participants to build a sense of community and connection online. London participants said they did build connections with the other group members.

> You do get, you do have an emotional connection [. . .] We've all had the same experience, we've all had a stroke, they're all totally different, you know [. . .] But you're, sort of, connected, you know, on that level. (Gwen, London)

Contributing together to a shared collective final piece was very meaningful to some participants:

> There's a piece of every one of us in every word. In every word. [. . .] And that's why, I think that's why this group is so gelled and so connected because all that stuff is in there. (Mickey, Donegal)

However, some said they would have liked more opportunities for informal chat and discussion.

> I wanted, just talk to them, one person at a time. . . . I suppose I keep myself to myself and just go along with everybody else, but I want to share myself, all of myself with everyone. (Sunflower, London)

In Donegal, online sessions began with a song being played as participants entered, and the artist took song requests and gave some time for people to mingle. This was useful in establishing a comfortable environment and warm welcome while people found their way to joining the Zoom. However, the connection was inhibited by the broadband issues for many trying to join in. Some found communicating harder online due to not being able to make eye contact with one individual or interpret body language in the same way as in person.

> I'd have a problem speaking over somebody, [. . .] you know, just getting used to [. . .] letting someone else speak and then, you know, knowing when there's a natural pause [. . .] it takes a wee while to get used to it on Zoom. [. . .] If the technology's not there, or if there's a delay you've got all those other extra problems. (Faye, Donegal)

Mostly, participants had a pragmatic attitude to online participation, saying that in some cases it was beneficial, enjoyable and a necessary alternative when meeting in person was not possible.

4)Support and resources needed

At face value, sessions involved two artists delivering a session either via Zoom or in person, but much more was going on behind the scenes. The facilitators had the responsibility of informing participants about the sessions and how to join, supporting them to join, and letting the artists know if any issues arose.

> In preparation for this, I linked up with the group I was working for at the time, [. . .] they were very well-resourced and were able to get laptops. [. . .] The big hurdle for a lot of them to participating was technology so I took them in to a meeting room . . . and went through the basics of Zoom with them and prepped for this project [. . .] To get people into the room was the trickiest bit, the participants into the room. So I got two co-workers [. . .] that could help me get everyone into the room. Because a lot of the time, I would have to ring participants to take them through and they would have to ring participants and step them through. (Facilitator, Donegal)

There were layers of planning and work to be done behind the scenes by artists and facilitators in London and Donegal.

> There are multiple strains of planning. You're not just planning your creative session, you're planning how to support individuals . . . paying attention to what people need at different points, communicating to the group, and keeping an eye on engagement across the whole group. There's a lot of admin to prepare for this, project communication, creative communication, and being mindful of any additional support an individual needs from a creative point of view. There's an awful lot to put into place so that the session runs really smoothly. (Artist, Donegal)

In both groups, participants asked for resources such as song lyrics to be made available to them to support their participation in online sessions. It became evident that clear, repeated explanations and reminders were essential. Both groups found it helpful to have a group webpage and WhatsApp group. The WhatsApp group was helpful for developing a sense of community as participants uploaded their various contributions, while the webpage was used to post lyrics, demonstration videos and information in one place.

Artists and facilitators needed to be aware of the specific needs of stroke and brain injury survivors, and to be able to adapt their plans accordingly. One aspect of this was to understand that people might be more likely to forget information. Participants appreciated being given reassuring group mantras throughout the programme.

> They had some very good key words. Things like, it's okay to be wrong. It's okay to forget. (John, Donegal)

It was important to participants that artists understood the impact of their neurological fatigue – something that caused many participants some anxiety when the intensity of sessions was set to increase. Having these concerns taken seriously and being able to adapt plans helped build trust.

> We said it, that they need to be thinking about us around fatigue [. . .] but they listened, they listened and took a lot of that stuff on board [. . .] you see that was the key for me. I think we

built up a huge amount of trust with the two girls [. . .] because they had listened to us. (Mickey, Donegal)

Discussion and Implications

Summary of findings

This study has found that for those whose ABIs occurred during Covid lockdowns, experiences of isolation and loneliness were severe, and the online performance arts programme gave people structure to their day, human interaction, and helped with their recovery. Different individuals valued different aspects of the programme, including music-making, movement, confidence-building, and sharing of experiences. For many – even those participating many years after their ABI – this was the first opportunity to process what happened to them with others in a similar situation, and this boosted their confidence. Online participation helped them to process their own identity as a stroke or brain injury survivor. Participants were able to develop "collective efficacy" (Vassilev et al., 2019) by contributing their individual experiences, developing a new personal community and contributing to a collective effort. We found various barriers and facilitators to online delivery, with the most significant barrier being the lack of internet connection in rural areas. Although technical issues such as delays and over-speaking could disrupt the flow of communication, most people felt that Zoom was an acceptable alternative to face-to-face sessions and valued online sessions. Delivering the programmes was resource-heavy, and many participants needed extra support in between sessions due to cognitive or communication difficulties. Some needed considerable support to connect online, including the provision of equipment, training to use Zoom, and verbal guidance to join sessions. Introducing resources such as WhatsApp groups and webpages supported participation, but also added to the demands on artists' and facilitators' time.

Overall experiences of online programmes in the context of previous research

Previous research has shown that performance arts programmes can be beneficial in improving health and well-being for people who have had a stroke or neurological condition (Fancourt & Finn, 2019; Schlaug et al., 2010; Baylan et al., 2018; Patterson, Wong, Prout, et al., 2018Patterson, Wong, Nguyen, et al., 2018). We found that online delivery and face-to-face delivery can create a different experience, but both have value and can create a sense of a shared community. The effects of an ABI on mental and emotional well-being, including problems of loneliness, isolation and reduced confidence, have been well documented (Ayerbe et al., 2013; Headway, 2009; Heinemann et al., 2002; Northcott et al., 2016). It has been noted that for many people these issues were compounded during the pandemic when restrictions reduced contact with healthcare professionals as well as friends and family (Ahmed et al., 2020; Stroke Association, n.d.). As with Wilkie et al. (2021) study, we found that being in a supportive environment with peers who understood them was important to participants and promoted a sense of belonging and connection. Similarly, an investigation into the Stroke Association's peer-support groups before and during the pandemic found that stroke survivors reported higher levels of loneliness than the general population, and participation in a peer-support group enabled them to manage their psycho-social health (Tarrant et al., 2022). Groups adapted well to moving online and continued to value having a social identity as

a group member, experiencing the group as a resource for social support, and having a sense of group connection (ibid), and this was also the case for our participants. The importance of rebuilding a self-concept after a brain injury has been highlighted (Ownsworth & Haslam, 2016). A key motif running through Rosetta Life's creative initiatives is that through "performing ourselves" – sharing their stories with an audience – participants find voice, build self-confidence and defy social stigma (Rosetta Life nd) but this principle had not previously been tested in an online delivery model. We found that these aspirations were achieved for the online participants. This rebuilding of confidence and identity has parallels with the Life Thread Model, which can be used to understand and adjust to identity change after acquired disability (Ellis-Hill et al., 2008).

Whilst some participants felt that online participation was adequate but inferior to meeting face-to-face, others valued not having to travel to sessions, being able to join when feeling low or physically less able, or being able to drop in when unable to join a whole session in person. This mirrors findings from research regarding online arts for health interventions with different populations, where shy or anxious participants expressed a preference for virtual sessions (Holland et al., 2022; Kocsis & Yellowlees, 2017).

Barriers and facilitators

As noted elsewhere, time and support can help to enable successful online engagement from people with ABI (Wilkie et al., 2021). We found that the time and support given to enable engagement were extensive. People with cognitive and communication impairments were able to participate and valued the programmes, and supporting resources via a webpage, WhatsApp and one-to-ones facilitated their successful participation.

Recommendations for future practice

People who have had an ABI have specific needs, therefore artists and facilitators delivering programmes require skill in performance arts co-production as well as an understanding of factors such as cognitive and communication impairment, neurological fatigue, and physical restrictions. Gustavson et al. (2021) investigated telerehabilitation for stroke survivors and noted that preparation before sessions, extra time for interventions, training in technology use, clear guidance and technical support are all keys to making it successful. People with ABI may need additional individual support, and a flexible approach is needed to manage challenges such as fatigue, for example reducing session length and building in breaks.

People in rural communities need broadband, especially as in-person attendance at groups often requires long car journeys. The scarcity of digital resources in rural and low-income areas has been noted as a barrier to online rehabilitation globally (Chen et al., 2017; Sarfo et al., 2018). It is likely that the same people are isolated physically and technologically (for example, due to being unable to drive), and people who are not engaging with peer-support groups in the community are less likely to find out about new opportunities. The pandemic exposed digital poverty and the "digital divide", which must be addressed to prevent a widening gap in access to rehabilitation, connection and engagement (Ayre, 2020; Seah, 2020; Watts, 2020).

Limitations and reflections

The study was conducted in a rapidly changing context of Covid restrictions, and it was necessary to adapt and allow flexibility to respond to the needs and preferences of participants as these measures eased. We considered it valuable to explore the programmes as the delivery models evolved and to encourage participants to compare and contrast their experiences of the different session formats. The digital research methods raised various considerations and decisions as the study progressed. For example, the main researcher was a member of both Whatsapp groups and all members were aware of this. There was often a temptation to contribute as a participant, e.g. by sharing pictures of nature or responding to comments from others. However, the researcher chose to have a participation boundary of only sending messages relating to the research process e.g. giving information about the research project. The researcher explored observing online sessions with the camera on and camera off, and observations on this are noted in examples of fieldnotes (see supplementary file S1: Examples of fieldnotes). Both modes enabled a feeling of getting to know participants, but keeping the camera on was a stronger form of participant observation and led to a sense of belonging and togetherness with the group. We reflected that joining in with activities allowed experiencing them from a participant perspective, such as when joyfully dancing on screen with others, and this was different from the more detached observations. Further exploration of the technological context would be fruitful, including specific advantages and disadvantages of Zoom versus rival platforms (e.g. Teams), suitability to facilitating group work, and issues pertinent to online research. This study adds to a new body of online research. In a scoping review comparing face-to-face with online collected accounts of health and illness experiences (Davies et al., 2020), it was noted that there is a risk of losing data "richness" when people are not physically copresent. While it is beyond the scope of this paper to explore the methodological approaches and implications in depth, we reflect that the combination of observed sessions and interviews mitigated this risk.

Donegal participants tended to be active, keen to travel to meet in person, and more likely to have difficulty connecting online. This, and the timing of delivery in relation to Covid restrictions, is likely to have influenced this group's greater tendency to favour face-to-face sessions. This study took place during rapid changes in Covid restrictions and attitudes towards social contact, so it would be valuable to revisit attitudes to online participation when in-person options have resumed fully.

Conclusions

Online participation in performance arts can be joyful and the opportunity to connect with other ABI survivors is valued as individuals continue to process and adjust to their changed lives. Although there is a strong desire from many to return to face-to-face events, some people will continue to benefit from options for online participation due to difficulties with travel, confidence or mood. Those providing online arts programmes for ABI survivors should be mindful of extra support and resources that may be needed. There is no need to exclude people with specific impairments, but extra support, guidance and one-to-one contact may be needed for people who have difficulties with communication, memory or thinking skills.

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Ethics

Ethical approval was granted by the King's College London PNM Research Ethics Panel, REC reference:HR/DP-20/21–22443.

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