An exploration of stroke survivors' perspectives on cycling and the use of electric bikes.

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ABSTRACT

Background

New and innovative approaches are needed to overcome the barriers to engaging people in physical and leisure activity after stroke. Outdoor cycling, including the use of adapted or electric bicycles, may be one approach. However, perceptions of stroke survivors on this topic have not yet been explored.

Purpose

To explore a sample of stroke survivors' perspectives, who expressed an interest in cycling, about cycling and the use of electric bicycles.

Methods

A convenience sample of stroke survivors were identified through focus groups at a 'Cycling after Stroke' event, local stroke support groups, and structured interviews at a national conference for stroke survivors. Quantitative data were analysed descriptively and qualitative data analysed thematically.

Results

Data were collected from 21 stroke survivors, seven of whom were current cyclists. All participants were independently mobile with, or without, the use of a walking aid. Themes oriented around the value of cycling (e.g. getting out of the house, doing something for yourself, and feeling part of a community); concerns and challenges (safety and negotiating adaptations); and how they could be overcome (starting slowly and identifying sources of assistance).

Conclusion

Outdoor cycling may be a worthwhile approach to increasing physical and leisure activity after stroke. However, barriers still exist and need to be addressed to provide inclusive opportunities for adapted and electric cycling for stroke survivors. Due to the small sample size and bias population, further research is needed to explore stroke survivors' perspectives on cycling to provide solutions to overcome the barriers identified.

INTRODUCTION

Despite a wealth of evidence supporting the role of physical activity in post-stroke recovery [1] and the prevention of recurrent strokes [2], low levels of physical activity persist amongst stroke survivors [3]. Six months after a stroke, over half of stroke survivors also report that their lives are lacking some aspect of social, recreational, or purposeful activity [4, 5]. Returning to outdoor activities has been identified as a particular concern for people after

stroke [6], with nearly half of stroke survivors experiencing outdoor mobility restrictions [7]. Barriers to activity after a stroke include concerns around balance and fear of falling [8], and a lack of services, transport and support [9, 10, 11]. Novel and innovative approaches are needed that can support stroke survivors in achieving recommended levels of physical activity (i.e. 150 minutes or more of moderate intensity physical activity per week [12]).

Cycling may be a feasible and acceptable way of increasing outdoor leisure opportunities for some stroke survivors. Some of the advantages of cycling are that of being seated whilst exercising [13], and the option of being in either an upright or semi-recumbent position [14] depending on the requirement of the user. Cycling is also a functional, repetitive activity [15] and encourages use of the affected side [14]. There is a growing body of evidence demonstrating the increased beneficial effects on wellbeing and self-esteem when exercising in natural environments opposed to synthetic or clinical environments [16, 17, 18]. Yet, the current evidence base for cycling after stroke is limited to stationary cycling in the early phases of rehabilitation [15, 19, 20, 21]. Additionally, there are recent developments in cycling, including the development of motor-assisted bicycles that have yet to be explored in the context of stroke. Electric bicycles (e-bikes) for example, have a battery-operated electric motor that can be utilised to assist the cyclist during cycling. Sales of e-bikes are increasing in the UK [22] with the reported benefits including a reduction in muscle fatigue, exertion, and physiological stress [23]. However, the use of these bikes and the perceptions of stroke survivors towards cycling on e-bikes has not yet been explored within in Ireland, the UK or worldwide to the authors' knowledge.

The aim of our study was to explore perspectives of a sample of stroke survivors' who expressed an interest in cycling, about cycling and the use of electric bicycles.

METHODS

This was a sequential exploratory mixed-method design [24] consisting of two phases - focus groups (phase 1) and structured interviews (phase 2) (see Figure 1).

Participants

For phase one, we identified a sample of stroke survivors with a range of post-stroke cycling experiences using a convenience sampling strategy. A flyer advertising the 'Cycling after Stroke' event was circulated to existing contacts who work with people with stroke. A local stroke support group expressed interest in the event but were unable to attend on the day so a follow-up visit to the group was organised. Participants were recruited for the focus groups through (1) a one-off 'Cycling after Stroke' event held at a university sports arena in July 2016; (2) a visit to a local stroke support group.

For phase two, participants were recruited for structured interviews at an exhibition stand at a national conference for people after stroke. Stroke survivors at the conference were asked if they were interested in taking part in a structured interview. To be eligible to participate in the study the person had to have had a stroke. Carers were allowed to be present. The researchers explained that by participating in the structured interview the participant was giving their voluntary consent to be part of the research project.

Data collection

During phase one, we held one focus group at the 'Cycling after stroke' event and two focus groups at the local stroke support group. Focus groups were selected to allow for interactive discussion [25] between participants who were likely to have a range of experiences of outdoor cycling after their stroke. A short topic guide consisting of open questions was used to structure discussions (Appendix I) which were audio recorded.

In the second phase, we collected data using structured interviews with consenting attendees at a UK Stroke Assembly, which is a national conference with a target audience of anyone who is affected by stroke. Focus group data, together with findings from the literature, were used to inform the development of the structured interview guide (Appendix I). In the exhibition area of the conference, both the research team and an electric bike company known to the team each had a stand. Due to the proximity of the electric bike stand to the research team's stand, and to minimize any bias, it was made clear to all potential participants on initial introduction that the researchers were conducting independent research relating to cycling and the use of electric bicycles after stroke. A member of the research team (JJ, OG) read each question of the structured interview aloud and recorded on paper the answers given and any extra verbal information provided by the participants.

Data analysis

Audio-recordings of the focus groups were transcribed and imported into NVivo11 for thematic analysis. The approach to analysis was deductive in nature, with a view to identifying and reporting patterns in the data set that reflected participants' perspectives on

the feasibility of participating in outdoor cycling and the potential utility of electric bicycles. Following the guidance by Braun and Clarke [26], transcripts were read a number of times for understanding. Two members of the research team (MF, AK) then independently analysed the transcripts to produce an initial set of codes. These codes were reviewed in conjunction with (NM) and collated into preliminary themes. The extent to which preliminary themes reflected the data set was checked, prior to producing a refined set of themes. To reduce the burden of participation, member checking was not carried out.

The quantitative data collected in the structured interviews were analysed descriptively (JJ, NG, OG) and compared with the themes from the focus groups.

Ethical approval and reporting

All participants had the opportunity to read an information sheet and then provided written informed consent to allow audio recording of focus groups prior to data collection. For the structured interviews, the researchers explained that the participant was giving their voluntary consent to be part of the research project as stated at the beginning of the structured interview sheet (Appendix I). This study conformed to the Declaration of Helsinki and received approval from the University of Central Lancashire Research Ethics Committee, number STEMH 474 (focus groups) and number STEMH 647 (structured interviews).

RESULTS

Characteristics of the sample

In total 21 stroke survivors took part, 14 males and 7 females. Eleven stroke survivors participated in phase one (three focus groups), and ten stroke survivors completed a structured interview for phase two (Figure 1). Of the eleven participants in the focus group, two were actively cycling, one using a custom recumbent three-wheeled bicycle and the other using a standard road bicycle. The remaining nine focus group participants were not currently cycling, but had recently had the opportunity to trial-adapted bicycles.

Of the ten participants in the structured interview, seven were male, three were female and 50% were over the age of 60 years. The average number of years since having their stroke was 9, ranging from 3 to 30 years. Five of the ten participants in the structured interviews were currently cycling, one using a balance bike, one using a tandem, one using an electric bicycle, and two using a standard bicycle. All participants were independently mobile with, or without, the use of a walking aid.

Insert Figure 1 here

Figure 1: Overview of data collection

Value of cycling

When asked about reasons for taking up cycling, or returning to cycling after their stroke, three themes were evident in the focus group discussions: (i) improved mood through being outdoors, (ii) doing something for yourself and (iii) being part of a community. These findings also emerged in the structured interviews; five participants identified that doing something for yourself and being part of a community as important. Health and fitness was the main reason for cycling, and three of the five reported social reasons for cycling.

During the focus groups, participants discussed how finding themselves stuck in the house after a stroke contributed to problems of low mood. Taking part in an outdoor activity, in the form of cycling, provided a valuable opportunity to counter this and enhance their wellbeing.

> I wanted to get out of the house, you feel cooped up in the house after a while, you want to be outside you want to breathe the fresh air and be away from being cooped up. That being cooped up adds to feeling a little bit more down as time goes on doesn't it ***#'Current cyclist using road bike***

Focus group participants stressed the importance of having the opportunity to do something for themselves after their stroke. A number of participants provided detailed reflections on their time in rehabilitation, where they felt their opportunity to assess risk, and make decisions for themselves, was often revoked. One participant provided the following example to illustrate their experience:

> …one weekend I thought 'I know! I'll get out the wheelchair and see if I can get up the stairs'…so I went up on my bum one step at a time and I got to the top I felt really great, like I achieved something. When I got back to rehab and I happen to mention to a physio passing or an OT, I don't know who to blame [laughter], a week or two later when they had a case conference and I was sitting here listening to them that I had done this awful thing and gone upstairs and I felt naughty as if I shouldn't have done it…and I think the whole pressure of 'be careful' and 'don't do that' I think needs to change with rehab, you know 'try this', 'do this', 'push yourself a little'; okay you fall over you're not going to break well not too badly anyway ***#Currently cyclist using custom recumbent bicycle***

Experiencing a sense of achievement after participating in cycling activities was evident across all of the focus group discussions. Participants emphasised the importance of 'giving it a go' by themselves and highlighted that the resulting tiredness was experienced positively.

> You know I wanted to do it independently I didn't want to go on one with the two seats, one of the helpers wanted to go one with me but I said no, it won't prove I have done it, I have got to prove I can do it ***#Non-cyclist but recently trialled cycling***

> I was so fatigued after the stroke that it was nice to have the cycling to create a different tiredness, a tiredness that I remembered from pre-stroke was because I was physically having a go, it was nice to feel that tired instead of fatigued from the stroke ***#'Current cyclist using road bike***

The final aspect discussed by participants was how cycling afforded them the opportunity to feel part of a wider community.

You know, since I've had this trike, one of the things that sort of amazed me when I'm cycling along and proper cyclists come past they wave…you are part of that group…and you're not labelled you know, we're all in this together! ***#Currently cyclist using custom recumbent bicycle***

…but the joy of it, the joy, like fitting helmets you know [laughter] took me ages to fit a helmet, and she's [coordinator] going "Don't take that bike, don't take that bike, I've got to check the tyres!" You know, so there was a lot of camaraderie with it which was the enjoyable bit. ***#Non-cyclist but recently trialled cycling***

Concerns around cycling

Participants reported a number of concerns that were most often oriented around safety and practical issues during both phases. Although some focus group participants were able to try two wheeled bicycles, the majority opted for a three-wheeled bicycle to accommodate concerns around balance. Five of the ten structured interview participants reported fear of falling as a discouraging factor, with three of the non-cyclists reporting additional concerns relating both to keeping hold of handlebars, and keeping feet on the pedals. Participants in the focus groups, who had the opportunity to trial bicycles, also expressed some concerns over adaptations that intended to overcome stroke related impairments, but could inadvertently increase anxiety or risk of falls for participants.

…because I thought maybe these bikes would be, depending if you've had a stroke, you can put a strap on the pedals, put a strap around the left hand side, put a strap around the right hand side depending on which foot is difficult, that's the best route

346 for you. But then I thought afterwards, you can't stop because if that foots on the
347 pedal you have to stop that way, getting your feet out you'll be collapsed and hit on
348 the floor. ***#Non-cyclist but recently trialled cycling***

349 Most participants said during the focus groups that they would be unlikely to cycle on their
350 own or on the roads due to safety concerns. Traffic was the primary reason for avoiding
351 cycling on roads and one participant joked:

352 On the cars coming too close I was told there is research, proper research, that showed
353 that cars go closer to cyclists in Lycra than they do to people not dressed in Lycra
354 [laughter]…so the secret is to look as unprofessional as possible! ***#Currently cyclist***
355 ***using custom recumbent bicycle***

356 These findings were echoed in the structured interview data where four of the ten participants
357 reported other road users as a discouragement from cycling.

358 **<u>Overcoming challenges</u>**

359 Focus group participants reported that (i) starting slowly, and (ii) having help could assist in
360 overcoming some of the identified concerns. For example, one participant discussed the
361 option of starting on an indoor training device to get used to being on a bike, with another
362 participant outlining that the local authority cycling sessions provided an opportunity to test
363 out cycling before potentially progressing to purchasing a bicycle of your own:

364 If you practice on these [bicycles in group sessions] I suppose and you're good with
365 them you could think, ah, maybe I could buy my own bike now that I'm used to it, so

366 it's a good way of testing if you could do it isn't it and then you can buy your own if
367 you progress ***#Non-cyclist but recently trialled cycling***

368 Participants in the focus groups also spoke about the need for practical support for
369 transporting, and getting on and off the bicycles. However, only two of the ten participants in
370 the structured interviews identified this as an issue. Perspectives on the potential value of
371 motor assistance were generally positive as many participants felt that they were unable to do
372 as much as they would have liked on the bicycles. Additionally, participants identified
373 disadvantages such as weakness in particular positions, being unable to stand on the pedals to
374 generate additional force, and other non-stroke related problems that affected their ability to
375 pedal that could be helped by using a motor assisted bicycle.

376 I persevered, I had it the same as him, I did two laps and the first lap was fairly easier
377 than the second one. It was just … it was impossible and I would have loved to carry
378 on but that was that. ***#Non-cyclist but recently trialled cycling***

379 Because I have something wrong with my groin, I had a fractured pelvis you see and
380 it's my left groin a bit. So then it [my leg] was so high I couldn't get my leg back
381 down with the pedal to get that going so electrical would have made it easier in that
382 instance ***#Non-cyclist but recently trialled cycling***

383 In the structured interviews, eight of the ten participants expressed that they would be
384 interested in using an electric bicycle but identified the price as the most discouraging factor.
385 The one participant who already owned an electric bicycle found it to be useful and practical.

DISCUSSION

We identified three themes in this study that captured the stroke survivors' perspectives of outdoor cycling. The themes related to the value of cycling, the concerns and challenges of cycling, and then how these concerns may be overcome. Values of cycling that were highlighted included getting out of the house and enjoying the fresh air. Participants also highlighted the potential social element provided when cycling in a group setting, and through feeling part of the wider cycling community. The benefits of group exercise that provide an opportunity for social engagement, especially with people who are experiencing similar health conditions, has been highlighted in the literature [8,27]. Additionally, greater engagement in valued activities has been shown to be positively associated with improvements in emotional well-being after stroke [28]. None of the participants in this study reported an interest in cycling for practical purposes, which is reflective of the common UK population [29].

Participants did however identify numerous concerns, the primary one being safety whilst cycling. Safety is often considered the most important factor influencing cycling participation in the general population, particularly for women, children and the elderly [29]. Although some participants felt confident to cycle on the road, the majority of participants identified that they would be prefer cycling in spaces where no traffic would be present. Safety also included concerns around balance, falling, and being able to keep upper and lower limbs safely in position when cycling. A correct bespoke setup is said to be essential for optimising performance [30]. However, for many participants this involves the use of large and weighty adapted bicycles with implications for manoeuvring the bicycles, and for transportation.

Having assistance from others was identified as a crucial element to overcome some of the identified challenges. Participants, in this small sample sized study, had generally positive perspectives on the use of motor assistance. Power assisted, or electric bicycles, are becoming increasing popular in some parts of the world [31]. More recently, there are examples of how electric bicycles have been adapted to accommodate impairments resulting from other neurological conditions (e.g. cerebral palsy [32]) which may provide some insight into the optimisation of motor assisted bicycles for a stroke population. Some of the perceived benefits of electric bicycles in the general population include an improved sense of health and wellbeing and being able to cover greater distances in a shorter period of time with less effort [22]. However, various barriers are still present, most notably the high cost, which was identified by the sample of stroke survivors in this study.

All participants in this study self-selected to take part at the events 'Cycling After Stroke', local stroke support groups and a national stroke conference. Therefore, bias was introduced to the convenient sample of participants recruited, due to the individuals attending the events being actively engaged in their rehabilitation and interested in cycling already. As such, the results may represent an overly positive view. All participants were also independently mobile with, or without, the use of a walking aid. There are likely to be additional limitations for more severely impaired stroke survivors that are therefore not represented in this study. Study participants had a mix of experiences of cycling, and the perspectives of the majority was based on a one-off recent experience of trialling adapted bicycles. Additionally, perspectives on the utility of electric bicycles are based on speculation, rather than experience, for the majority of participants.

CONCLUSION

Outdoor cycling may be a worthwhile approach to increasing physical activity after stroke, but further work is needed to develop solutions to existing barriers to participation. The likely benefits of this approach may include increased opportunities to get out of the house, participation in 'green exercise' and increased social contact with other stroke survivors and the wider cycling community. This study has highlighted that barriers still exist for people after stroke who are interested in cycling, and would need to be addressed to provide inclusive opportunities for adapted and electric cycling for stroke survivors. However, due to the small sample size and bias population used, the findings of this study cannot be generalised. Therefore, more research is needed to explore stroke survivors' perspectives on cycling to provide solutions to overcome the current barriers identified.

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Declaration of interest

The authors report no conflicts of interest.

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Appendix I: Data collection tools

A. Focus group topic guide

- What made you/would make you want to start cycling in the first instance?

- What were/would be your concerns/anxieties around cycling?

- How could these concerns/anxieties be overcome?

- What would you think about having a bicycle with motor assistance?

- What would your preferences be for participating in cycling?

B. Cycling after Stroke: Structured Interview

By completing this structured interview and returning it to the principal researcher, you give your voluntary consent to be a part of the research project and agree that the information collected can be used for further analysis as a part of the project.

You are able to withdraw from the study at any time during the structured interview. However, as all information you give is anonymous, once the completed structured interview has been filed you will not be able to withdraw.

We would really appreciate your feedback regarding cycling after stroke. All responses given will remain anonymous.

Interviewer's name: _____

Please answer all the questions as fully and as honestly as possible.

Age group

❑ 18-25 ❑ 26-35 ❑ 36-44

❑ 45-60 ❑ 60+ ❑ Prefer not to say

Gender

❑ Male ❑ Female ❑ Prefer not to say

How long is it since you had your stroke? _____ years _____ months

Cycling

Q1. Do you currently cycle?

❑ Yes ❑ No ❑ Prefer not to say

If yes, for what reason(s) do you cycle? Tick all that apply.

❑ Social (e.g. cycling with others, networking)

❑ Practical (e.g. commuting)

❑ Fitness/ health & wellbeing

If no, would you be interested in cycling?

❑ Yes ❑ No ❑ Prefer not to say

Q2. Do you or have you ever owned or used a bicycle?

❑ Yes ❑ No ❑ Prefer not to say

Q3. Is there anything that is discouraging you from cycling at present?

❑ Yes ❑ No ❑ Prefer not to say

578 If yes, please tick all that apply:

579 Physical limitations:

- ❑ Feet slide off the pedals
- ❑ Unable to hold onto handlebars
- ❑ Afraid of falling off due to poor balance
- ❑ Not enough strength or endurance
- ❑ Other health issues, (eg, poor vision or hearing, other medical conditions, etc). **Please specify below**:

_____

580 Safety concerns:

- ❑ Other road users
- ❑ Nowhere safe to cycle locally
- ❑ Other _____

581

582 Other considerations:

- ❑ Lack of confidence

- ❑ Fear of being judged by others for riding a bike
- ❑ Practicalities, (e.g. needing to plan ahead for this, difficulties transporting bike).

Please specify below:

_____

- ❑ Other: _____

583

584 **Electric bikes**

585 Q4. Have you heard of an electric bike?

❑ Yes ❑ No ❑ Prefer not to say

586 Q5. Would you be interested in using an electric bike to cycle either as a hobby or form of

587 exercise?

❑ Yes ❑ No ❑ Not applicable

588 Q6. Is there anything that is discouraging you from cycling on an electric bike?

589 Safety concerns:

- ❑ Speed of an electric bike

- ❑ Other: _____

590

591 Other considerations:

- ❑ Lack of confidence
- ❑ Fear of being judged by others for riding an electric bike
- ❑ Price of the electric bike
- ❑ Practicalities, (eg, charging the battery, concerns about battery running out and needing to plan ahead for this, difficulties transporting electric bike, weight of the electric bike).

  Please specify below:

  _____
- ❑ Other: _____

592

593 Q7. Looking at the adaptations shown please tell us which of the following you would

594 consider acceptable to use? **Tick all that apply**.

Arm/Hand	Leg/Foot	Balance
1 ❑	6 ❑	11 ❑
2 ❑	7 ❑	12 ❑
3 ❑	8 ❑	13 ❑
4 ❑	9 ❑	
5 ❑	10 ❑	

If you would require any other adaptations, please write below.

_____

Q8. Have you tried the electric bike today?

❑ Yes ❑ No ❑ Prefer not to say

Q9. Would you recommend this electric bike to others?

❑ Yes ❑ No ❑ Maybe ❑ Don't know

Q10. An electric bike costs around £1,000. Having seen this electric bike with adaptations today, how likely would you be to buy it?

❑	❑	❑	❑	❑
Extremely unlikely	Not very likely	Quite likely	Extremely likely	Prefer not to say

Q11. How affordable is this electric bike for you?

❑	❑	❑	❑	❑
Completely unaffordable	Not very affordable	Quite affordable	Completely affordable	Prefer not to say

602 Q12. How practical would using an electric bike be for you?

❑	❑	❑	❑	❑
Extremely impractical	Not very practical	Quite practical	Extremely practical	Prefer not to say

603 Q13. How useful would it be for you to have an electric bike?

❑	❑	❑	❑	❑
Extremely useless	Not very useful	Quite useful	Extremely useful	Prefer not to say

604 Q14. How acceptable is this electric bike with adaptations to you?

❑	❑	❑	❑	❑
Extremely unacceptable	Not very acceptable	Quite acceptable	Extremely acceptable	Prefer not to say

605 Q15. How concerned are you about safety when using this electric bike?

❑	❑	❑	❑	❑
Extremely	Not very	Quite	Extremely	Prefer not

unconcerned	concerned	concerned	concerned	to say

606 Q16. How likely is it that this electric bike would reduce any imbalances between you and
607 those around you?

608

❑	❑	❑	❑	❑
Extremely unlikely	Not very likely	Quite likely	Extremely likely	Prefer not to say

609 Q17. Do you have any other comments about cycling, the electric bike or the adaptations?

610 _____

611 _____

612 _____

613

614 Thank you for completing this structured interview!

615

616

Figure 1

Figure 1: Overview of data collection