Experiences of an exercise referral scheme from the perspective of people with chronic stroke: a qualitative study

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Abstract

Objective To explore stroke survivors’ experiences of undertaking exercise in the context of an exercise referral scheme for people with chronic stroke.

Design A qualitative design, using semi-structured interviews within a constructivist framework to explore the experiences of individual participants. Verbatim transcripts were thematically analysed. Rigour mechanisms included respondent validation, peer checking, and reflexivity.

Setting An exercise referral scheme, based at a leisure centre in South London.

Participants Nine community-dwelling stroke survivors took part; 5 male and 4 female, mean age 51 years (range 37–61 years); time post stroke 1–4 years, with mixed ethnic backgrounds.

Findings Participants described greater physical and psychological well-being following participation in the exercise referral scheme. Categories that emerged were: improved exercise engagement and confidence, more internalised perceptions of control and enhanced lifestyle, work and social roles. Categories linked to form a master theme, labelled: ‘Exercise Referral Scheme as a catalyst for regaining independence.’

Conclusions This study supports the value of exercise referral schemes in enabling people with stroke to engage in exercise. For participants in this study, the scheme seemed influential in the process of regaining independence.

Keywords: Stroke; Exercise; Physical activity; Exercise referral scheme; Community

Introduction

Globally, fifteen million people suffer a stroke each year and with five million being left permanently disabled, stroke places a considerable burden on family, community and economy [1]. In England, stroke is the largest single cause of adult disability; over 900,000 people live with the consequences of stroke, with associated costs estimated at over seven billion pounds per year [2]. The impact of stroke on individuals may include reduced independence, low mood, sensorimotor impairment and decreased fitness.

Reduced physical fitness is common following stroke [3], presenting a risk for recurrent stroke, cardiac disease and fall-related fractures [4,5], and a barrier to community re-integration [6]. With more people surviving strokes [7] and government policies shifting health care from hospital towards community [8], improving physical fitness in community-dwelling stroke survivors is a priority.

A growing body of evidence demonstrates that exercise, defined as structured and repetitive physical activity (PA) that is usually planned to enhance fitness [9], can improve a range of fitness parameters after stroke [10]. However, evidence also suggests that PA must be maintained to sustain benefits [11]. UK national clinical guidelines recommend regular exercise participation and aerobic training where possible, as part of a long-term strategy after stroke [12–14].

Studies of PA maintenance after stroke are scarce. One report demonstrated immediate reductions in PA follow-
ing completion of an exercise programme, and return to low levels three months later [15]. General population surveys have found that maintaining sufficient levels of PA is difficult [16]. To encourage ongoing exercise participation among different populations, exercise referral schemes (ERS) were developed in the UK [17]. However, four randomised controlled trials (n = 1200 in total) found a return to pre-intervention exercise levels at 12-to-52 weeks after completing an ERS [18–23]. Reasons for this decline in exercise behaviour are unclear, mainly due to a lack of qualitative data. Exercise behaviour is complex; one review identified over 70 correlates of exercise participation in adults [24]. With the ERS model now well established, knowledge of participants’ experiences with this type of service is essential to optimise uptake and ongoing PA participation. Although the value of patient experiences in service design and delivery is well recognised by the UK National Health Service (NHS) [25] and government policies [26], little is known about stroke survivors’ experiences of exercise in the context of an ERS.

The first qualitative study to formally explore the experiences of stroke survivors of an exercise intervention [27] was associated with a clinical trial [11] and found that participants had enjoyed the classes, felt empowered to take more control over their recovery, and more motivated to get out of the house and undertake other activities. Most exercise participants continued with an active lifestyle afterwards, and felt their quality of life had increased. Another clinical trial [28] included an exploration of stroke survivors’ perceptions of a community-based scheme combining exercise with education [29]. Exercise and goal setting were valued as positive actions that enabled improvements in physical function and confidence. However, these interventions were delivered within the context of clinical trials, and the findings may not generalise to routine clinical practice.

To our knowledge, only one study has explored experiences of a community-based ERS for stroke survivors [30], and included people with stroke, fitness instructors who ran the scheme and referring physiotherapists. Four main themes emerged: the role of the ERS in continuing rehabilitation following physiotherapy discharge; concern regarding instructors’ level of knowledge about stroke; low levels of supervision and interaction with instructors; and suggested improvements to the scheme, including closer contact between referring physiotherapists and exercise instructors. However, perceived impacts of the scheme on participant’s lives were not explored, and it was not possible to isolate the experiences of stroke survivors.

In summary, published literature on exercise after stroke focuses primarily on physical impairments and activity limitations, with little information on perceptions and experiences relating to exercise and any psychosocial impacts of exercise referral schemes. Therefore, the aim of this study was to explore the experiences of people in the chronic phase after stroke, who participated in a community-based, physiotherapy-led ERS.

**Method**

**Study design**

Individual experiences were explored in depth using a constructivist qualitative approach that focuses on socially constructed multiple realities [31]; an interpretivist perspective that appreciates individuals’ values and meanings; and phenomenological methodology, whereby the researcher ‘brackets’ personal understandings when deriving meaning from the data [32].

One-off, one-to-one semi-structured interviews enabled an individual focus and coverage of important topics without limiting responses [33]. Approval was granted by the Research and Development centre attached to the Primary Care Trust that was responsible for the ERS, and by both ethics committees of the lead researcher’s Higher Education Institution and NHS employer.

**Sample population and recruitment**

The study context was an exercise programme provided through an ERS based at a South London leisure centre, supervised by a chartered physiotherapist and specific to people with neurological conditions. The ERS is defined in this study as “the referral to, and uptake of, a physiotherapist-led exercise programme”. Individually tailored gym-based exercise took place in a group format, twice weekly, for up to three months. Participants were generally referred by a physiotherapist at least six months after their stroke.

The study population included people with a primary diagnosis of stroke who had attended the ERS within the previous two years, over which recall of experiences was considered realistic. To capture varied experiences, attendance levels and ERS completion were not prerequisites for selection. Potential participants were identified by the lead researcher (HS), using NHS patient records and were sent invitation letters, information sheets and consent forms. Those returning consent forms were telephoned to screen for factors that would render an in-depth interview unfeasible, including inability to engage in conversation, a voice potentially incomprehensible on audiotape, or inability to recall their ERS experiences. Participants were offered interviews at their venue of choice. It was thought unethical to undertake further measures to increase recruitment rate.

**Procedure**

The lead researcher (HS) was a female chartered physiotherapist with 2 years’ general experience, and 3 years specialising in neurology. She was employed at the ERS as the primary clinician, but only after participants in this study had been discharged, minimising impacts from prior knowledge or relationships. Participants were aware of her background but the importance of their views and experiences was emphasised.
Table 1
Summary of topic guide.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Example question</th>
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<tbody>
<tr>
<td>Demographics</td>
<td>Confirm age, time of stroke, when attended ERS</td>
</tr>
<tr>
<td>Meaning of exercise to individual</td>
<td>What do you think of when I say ‘exercise’?</td>
</tr>
<tr>
<td>Past experience of exercise</td>
<td>Before your stroke, how active were you? What sorts of things did you do?</td>
</tr>
<tr>
<td>Impact of stroke on exercise behaviour</td>
<td>How did your stroke affect the exercise that you could do?</td>
</tr>
<tr>
<td>Experience before attending ERS</td>
<td>Before you went to the ERS, what did you think it would be like? Why do you think you thought that?</td>
</tr>
<tr>
<td>Experience of ERS</td>
<td>How did you feel about exercising in this way?</td>
</tr>
<tr>
<td>Transition from ERS to independent exercising</td>
<td>Is there anything you didn’t enjoy? Why was that?</td>
</tr>
<tr>
<td>Current status</td>
<td>Is there anything from your experience of ERS that affects your life now? Why is that?</td>
</tr>
<tr>
<td>The future</td>
<td>Do you have any future plans when it comes to exercise?</td>
</tr>
</tbody>
</table>

ERS: exercise referral scheme.

An interview topic guide was developed to address the study aims, informed by relevant literature. The questions, summarised in Table 1, explored experiences of accepting a referral to an exercise programme, participating, and perceptions of any impacts. Participants’ experiences of exercise before stroke, and their understanding of the word ‘exercise’ were explored. Maintenance of exercise participation after programme completion was also addressed, based on concerns raised by Morgan [34]. Questions were structured chronologically to aid recall, and phrasing provided scope for additional areas to emerge [35]. Only the interviewer and interviewee were present at each interview.

A video-recorded, role-played pilot interview enabled refinement of the interview technique and further development of the topic guide. Review of this pilot interview identified possible influences on the credibility of the participants’ responses. This reflexive process continued throughout data collection through a research diary to minimise effects biases and presuppositions [32].

Data analysis

Interviews were audiotaped and transcribed verbatim. Participant verification of initial interpretation took place using interview summaries. In-depth analysis used an iterative coding process, moving towards greater levels of abstraction [36]. Text was first read and re-read by the lead researcher, and annotated with labels that described concepts (first level themes). Similar labels were grouped where they described related ideas, and given another label (second level theme). Further abstraction led to the creation of categories (third level themes), and finally a master theme (Table 2). This was iterative, as text from all interviews was analysed. Analysis was considered complete when no new themes were defined and all relevant text was incorporated in a theme. A word processing package was used rather than a qualitative data analysis programme; while the latter is useful for data management, it does not perform the thinking, and can create distance from the text [37]. A sample of themes and contributing text units was reviewed by an experienced qualitative researcher (CB); discussion led to consensus between researchers, which enhanced dependability of the analysis [38].

Results

Participant characteristics

Of forty-one invited participants, 12 consented, three of whom could not be included: one was not contactable, one was not sufficiently fluent in English, and one could not recall ERS participation. Interviewed participants included four female and five male community-dwelling adults (mean age 51; range 37–61 years), who had had a stroke one to four years previously. Four were of White English, one White Irish, and four Black African ethnic origins. Interviews lasted 45–80 minutes. Six occurred in participant’s homes, one at their workplace, and two at a hospital office.

Categories

Four categories emerged: exercise engagement (i.e. relevant behavioural changes); improvement (i.e. individuals’ interpretations of physical and psychological improvements); control (changing views regarding who was responsible for increased feelings of independence); and finally, confidence (i.e. a growing sense of self-confidence in the individual’s ability to exercise). The account focuses on varied experiences, rather than consensus views. Pseudonyms have been used throughout.

Exercise engagement

Between the stroke and ERS, participants recalled slowing down and making adjustments to lifestyle, work and social roles. This pace-change appeared to be challenged by ERS attendance, which facilitated increases in activity levels within sessions, and outside the ERS:

‘Before I started going [to the exercise referral scheme], I wasn’t thinking about exercise, and I wasn’t thinking about anything, other than sit at home, eat and watch television. When I started, at least they gave me that ability, they gave
me that push … So thereafter, I just cook up something in my head, go down the stairs or go down the street.’ [Louise]

Increased activity generated feelings of normality and independence:

‘Because when I do exercise, when I go out, it puts me back to normal. And when I see others walking, what would make me not walk? I am not disabled. The stroke has not made me disabled, so I walk.’ [Mary]

Improvement

Participants identified improvements following ERS participation, predominantly in fitness, strength and movement:

‘If I didn’t go [to the exercise referral scheme] … it would take a long time for me to be moving around … I gained more strength … [the exercise referral scheme] really helped my moving, my walking, how I am doing everything.’ [Beth]

Several participants also identified ‘immediate’ improvements to mood following the exercise sessions, perceived as evidence that the stroke was ‘going away’ and that they were ‘getting better’. Positive feelings of happiness and enjoyment were described, and exercise became a source of pleasure in itself:

‘When I finish exercising and I feel so good, so content. … By the end of the day you feel good, you know, you say ‘I feel good, my health is coming back’ in your head.’ [Peter]

Control

Interestingly, participants attributed perceived improvements during initial rehabilitation to external factors, such as the physiotherapist, God, the consultant, or the health service in general, and perceived themselves as dependent:

‘When I’d gone walking, I’d always had somebody from the ward going out with me and holding me up, or I was in the wheelchair and I hated it.’ [Jim]

When recalling ERS participation, interviewees expressed the importance of their own personal qualities to successful recovery and increasing independence, attributing improvements to internal factors such as motivation, willpower and self-determination:

‘The physio is something else, the exercise programme is something else, you yourself willing to do something for yourself, and having that willpower to proceed and progress what you want to do is another thing.’ [Louise]

Confidence

Low confidence was described as a barrier in relation to initial ERS attendance. Attitudinal barriers in the form of reservations about the gym environment were described, as well as physical barriers en route from home to the leisure centre.

‘My own sense of … my self-esteem was very low anyway, the fact that I couldn’t physically do things I used to take for granted, and I don’t particularly like that kind of macho culture anyway. I wouldn’t want to expose myself to it. I’d have been worried about people poking fun.’ [Tony]

‘Initially when I was discharged from hospital, I want to go to the gym. When I come out from my house and I look at the stairs, it’s like I want to fall over, I go back inside and shut the door.’ [Louise]

Confidence that was specifically related to exercise increased within the ERS, facilitated by the physiotherapist and group dynamic:

‘I mean me, all I can say is that I had determination. I didn’t have the confidence, but I had determination and they [physiotherapists] gave me the confidence. But when I saw I could start to do a thing, that was it. Once I got to start doing it I looked at my sheet and saw I did that little bit more than last week.’ [Jim]
Increased confidence also affected more general social and occupational activities:

‘I was ashamed, limping all the time and using a walking stick. But when I got there, I saw people that were even older and even younger than me and they were there for numerous reasons. And these are people that say, when we finish using the gym, ‘I am going to the high street for window shopping’, and I tag along… At times, I just walk into the shopping centre with confidence…’ [Louise]

One participant expressed a belief that the ERS contributed to increased confidence, and felt able to return to work:

‘I started work and I was able to start where I left off… and if I had not gone through this I would not have had the confidence…It is not the medication that has made me better, it is the exercise…’ [Peter]

Master theme

The categories emerging from the data describe a journey through engagement with exercise after stroke, yielding physical and psychological improvements, increased feelings of personal control, and raised confidence. These personal developments appeared to be linked in their contributions to regaining independence. Thus, the master theme that emerged was entitled: ‘ERS as a catalyst for regaining independence’.

These results are summarised in Table 3, demonstrating the audit trail from second level themes, through categories, to the master theme.

Table 3
An overview of the master theme and contributing categories and themes.

<table>
<thead>
<tr>
<th>Master theme</th>
<th>Constituent categories and definitions</th>
<th>Second level themes contributing to the category</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘ERS as a catalyst for regaining independence’</td>
<td>1a. Exercise engagement: behavioural changes regarding exercise</td>
<td>1ai. Links between confidence and exercise engagement</td>
</tr>
<tr>
<td></td>
<td>1b. Control: participants’ changing views on who/what was responsible for them gaining independence</td>
<td>1aii. Links between physical improvement and exercise engagement</td>
</tr>
<tr>
<td></td>
<td>1c. Confidence: the progression of feelings of self-confidence and beliefs in exercise ability</td>
<td>1aiii. Exercise engagement and perceived exercise restrictions or opportunities</td>
</tr>
<tr>
<td></td>
<td>1d. Improvement: Physical and psychological improvements and their meanings to participants</td>
<td>1aiiv. Reflections on the self and exercise engagement</td>
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<td></td>
<td></td>
<td>1b. Links between the rehabilitation setting and perceptions of control</td>
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<td></td>
<td></td>
<td>1b. Varying roles of the physiotherapist</td>
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<td></td>
<td></td>
<td>1bii. Perceptions of control and exercise behaviour</td>
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<tr>
<td></td>
<td></td>
<td>1b.iv. Perceptions of control and the discharge procedure</td>
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<tr>
<td></td>
<td></td>
<td>1c. Links between the rehabilitation setting and confidence</td>
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<tr>
<td></td>
<td></td>
<td>1ci. Links between perceptions of the physiotherapist and confidence</td>
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<tr>
<td></td>
<td></td>
<td>1cii. Links between perceptions of the group and confidence</td>
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<tr>
<td></td>
<td></td>
<td>1ciii. Links between independence, emotions and confidence</td>
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<tr>
<td></td>
<td></td>
<td>1civ. Confidence and social situations</td>
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<tr>
<td></td>
<td></td>
<td>1d. Links between improvement and beliefs about the exercise programme</td>
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<tr>
<td></td>
<td></td>
<td>1dii. Links between improvement and beliefs about exercise generally</td>
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<tr>
<td></td>
<td></td>
<td>1diii. Links between beliefs and feelings about exercise</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1div. Impacts of beliefs and feelings about exercise on exercise engagement</td>
</tr>
</tbody>
</table>

Discussion

Main findings

The findings from this study suggest that the ERS encouraged participants to become more active within and outside the sessions. Participants reported physical and psychological improvements, including fitness, strength, movement, mood and enjoyment. Locus of control appeared to shift from predominantly external during initial rehabilitation, to more internal during the ERS. Initial barriers to exercise participation had to be overcome, including concerns about getting to the venue, low self-confidence, and feelings of self-consciousness. Generic and PA-specific self efficacy increased, and the group format appeared to induce feelings of independence and normality.

Reduced independence is a key problem after stroke with two thirds of people experiencing limitations in at least one activity of daily living five years after stroke [39]. The current study revealed that participants had been involved in a slow process of regaining independence, in which the ERS acted as a catalyst, enhancing perceptions of greater normality, confidence and independence.

These findings contribute to the literature on exercise after stroke; one systematic review highlighted the lack of research relating to effects of exercise on disability, dependence, mood, self-efficacy and locus of control [10]. The current findings resonate with other qualitative work, where stroke survivors reported that exercise enhanced physical function, empowerment and confidence [27,29]. When looking beyond
literature specific to stroke, the significance of ERS participation was also identified by one study in an ageing population and one in people with mental ill-health [40,41]. Recovery of elements of the self was described, as participants were said to ‘reconnect with their human potential’ [40] and ‘reclaim a sense of personhood’ [41]. This may be particularly important for stroke survivors who have experienced dramatic changes in their physical, emotional and social worlds. In the current study, one participant reported feeling ‘completely lost . . . the stroke took my life away from me; everything I could do, everything that meant anything to me’ [David]. Evidently, such qualitative data deepen our understanding of the impact of exercise on the self as a whole.

All consenting participants in this study experienced positive changes in their physical and psychological well-being, some up to four years post-stroke. This supports UK national clinical guidelines for stroke [12–14], which advocate the promotion of an active lifestyle where possible. The ERS provides one strategy to this effect and further collaboration between physiotherapy and local health and leisure services is required to facilitate access to exercise after stroke [14,42–44].

Implications of findings for exercise after stroke referral schemes

Service development requires evidence of efficacy, and existing ERSs have been criticised for using primarily impairment-orientated outcomes (e.g. blood pressure), and being insufficiently client-centred [18]. The current study suggests that ERS evaluation would benefit from additional measures relating to mood, self-efficacy and locus of control.

Low recruitment and attendance must also be addressed [34]. A survey found that the three most common barriers to exercise after stroke were programme cost, lack of transport and lack of knowledge about local exercise facilities [45]. In the current study, some participants said they were uncomfortable around able-bodied exercisers, which could be exacerbated in a gym setting where the focus is often on physical perfection. To reduce perceived barriers to exercise after stroke, opportunities to exercise in a peer group and solutions for environmental barriers (e.g. providing transport) should be offered where possible, as recommended in the best practice guidelines [44].

Study limitations

The credibility of the data must be considered. The sample was small, with a low response rate, possibly due to recruitment by mail. Although not ideal, this was approved on ethical review. However, the sample was consistent with the study design and aims of increased depth of insight that can be transferred to similar contexts, rather than generalisability of results [46]. Data were extensive, with 45–80 minutes of interview per participant. While data saturation through repeated interviews was not possible within the scope of the study, analytical saturation was achieved [46].

The sample was not necessarily representative of the wider stroke population, with varied demographic characteristics and a low mean age, which may have affected ERS uptake. Similar positive perspectives on ERS participation were expressed, which may have been influenced by social desirability and convenience sampling. The views of those who did not accept an invitation to the ERS were not addressed, and future research should use purposive sampling to explore successful and unsuccessful experiences. It would also be valuable to collect data relating to time since participation and frequency of participation.

The ethnic diversity was representative of the local area [47], but in some cases, vocabulary and expression may have affected interpretation of responses. A field diary was used in order to reflect on possible influences during data collection and analysis. There were insufficient resources to provide communication support, and regretfully, persons with memory impairments or communication difficulties were therefore excluded, as is frequently the case. The resulting bias is acknowledged.

Five out of nine participants returned and agreed with the interview summaries, enhancing credibility of initial interpretation. Respondent validation of the final themes was considered less useful because not all themes related to the views of every participant [48]. Although the lack of verification of four summaries limits credibility, it was not considered unethical to pursue the missing summaries. On balance, the results have credibility and were generated through a rigorous process. The relevance of these findings to further settings must be evaluated by the reader, using the contextual and demographic information provided [32].

Conclusions

This study aimed to explore stroke survivors’ experiences of exercise in the context of a community-based ERS. Participants perceived the scheme as an important driver in the process of regaining independence, as they experienced improvements in physical and psychological function. They also reported a shift from an external to a more internal locus of control and improved general and exercise-specific self-efficacy, which carried over into activity outside the exercise sessions. The findings from this – albeit small-scale – study support exercise referral schemes as a method for increasing physical activity after stroke. However, some barriers to exercise participation also emerged, and further research is required to explore how uptake and continued exercise engagement after stroke can be optimised.

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Conflict of interest: The authors report that there were no conflicts of interest.

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