Investigating changes in quality-of-life after high-dose high-intensity upper limb rehabilitation in chronic stroke survivors: A mixed-methods analysis of the Queen Square Programme

Clinical messages

- Chronic stroke survivors improved in arm activity and quality-of-life scores following the Queen Square intensive upper limb rehabilitation programme.
- Although stroke survivors demonstrated comparable improvements in arm activity measures, their quality-of-life and social participation were significantly shaped by mental health and psychosocial factors.
- Neurorehabilitation should consider these important factors as part of a holistic approach.

Introduction

Stroke is a leading cause of adult mortality and disability globally[1] with quality-of-life in chronic stroke survivors being a critical aspect of long-term recovery[2]. Upper limb dysfunction is a common and persistent impairment following stroke[3], with qualitative studies highlighting that difficulties with upper limb function negatively influence independence in personal care, participation in meaningful activities, and the maintenance of social and familial roles[4,5]. Impairments in upper limb function are consistently associated with reduced quality-of-life, social participation, and overall well-being[5,6,7].

The strong link between upper limb dysfunction and quality-of-life suggests we should have a better understanding of the impact of one form of rehabilitation on other domains such as quality-of-life. For example, better upper limb outcomes improve subjective wellbeing at one-year post-stroke[8] and lead to higher confidence and accountability for recovery[9]. Conversely, poorer outcomes exert a negative influence on self-esteem and sense-of-self[5]. Targeted post-stroke upper limb interventions can improve overall quality-of-life or certain quality-of-life domains such as social participation[6], but generally non-domain specific effects have not been reported[10].

The Queen Square Upper Limb[11] programme provides targeted high-intensity, evidence-based upper limb rehabilitation focusing on long-term recovery. The overall approach is very much based on individualised goals (see TIDieR checklist[12]) and we were interested to look at the impact of this form of targeted neurorehabilitation on broader aspects of a person's life. More specifically, although these data do not come with a control group, in a cohort of chronic stroke patients receiving no ongoing rehabilitation, they provide a unique opportunity to explore the following research questions:

a) Do measures of self-reported quality-of-life of stroke survivors change with intensive high dose upper limb rehabilitation?
b) Does self-reported quality-of-life on admission influence upper limb activity and participation after intensive high dose upper limb rehabilitation?
c) What are the beliefs and psychosocial factors influencing social participation as a component of quality of life among stroke survivors following their involvement in the Queen Square Upper Limb rehabilitation programme?

Methods

Study design

This study used a mixed-methods sequential explanatory design. The quantitative phase comprised a before-and-after uncontrolled design, using routinely recorded stroke-specific quality-of-life data measured at four time points. Quantitative data guided purposive sampling for the qualitative phase, selecting participants with the highest and lowest change in Stroke Impact Scale participation scores (admission to six-month follow-up), for one-to-one semi-structured interviews.

A constructionist research paradigm, with a phenomenological approach was used as an opportunity to gain insights into the lived experience of recovery, participation and quality-of-life after stroke and the rehabilitation programme.

Ethical considerations

Approval as a service evaluation gained from City, University of London Research Ethics Committee (MRes/17-18/15) for the quantitative phase. Ethical approval granted from NHS Research Ethics Committee (18/NE/0101) for the qualitative phase of the study. The participants voluntarily signed a consent form before being recruited for interview.

Setting

The Queen Square Upper Limb intensive rehabilitation programme,[11,12,13] is a UK NHS service , providing 90 hours of intensive upper limb neurorehabilitation over three weeks using a holistic, individualised approach with treatment for all levels of impairment, activity and participation. Progress is monitored with reviews at six-weeks and six-months.

Participants

Stroke survivors who completed the Queen Square Upper Limb programme between July 2016 and March 2018 were included in the analysis provided they had completed the Stroke Impact Scale 3.0 (SIS) at admission (T1), discharge (T2) six-weeks (T3) and six-months (T4) post-discharge. Stroke survivors were eligible for the study if they were aged 18 years or older, had upper limb paresis, and a confirmed diagnosis of stroke. Stroke survivors were excluded if they did not complete the measures over each time point or attend follow-up appointments. This included those that had severe cognitive or communication impairment or were from a non-English speaking background (translator not always available) impeding accurate completion of the self-reported Stroke Impact Scale.

Of the included participants, the ten stroke survivors who exhibited the highest changes in the Stroke Impact Scale-participation domain from admission to six-months were identified. In addition, the ten stroke survivors who exhibited the lowest changes were also identified. From these, to take part in semi-structured qualitative interviews, we pragmatically recruited the first five consenting participants from each of the higher-change (n=5) and lower-change (n=5) groups, purposively selecting for diversity in gender, age and time post-stroke. Figure 1 below presents the participant flow sheet. Table 5 in results outlines interview participant demographics.

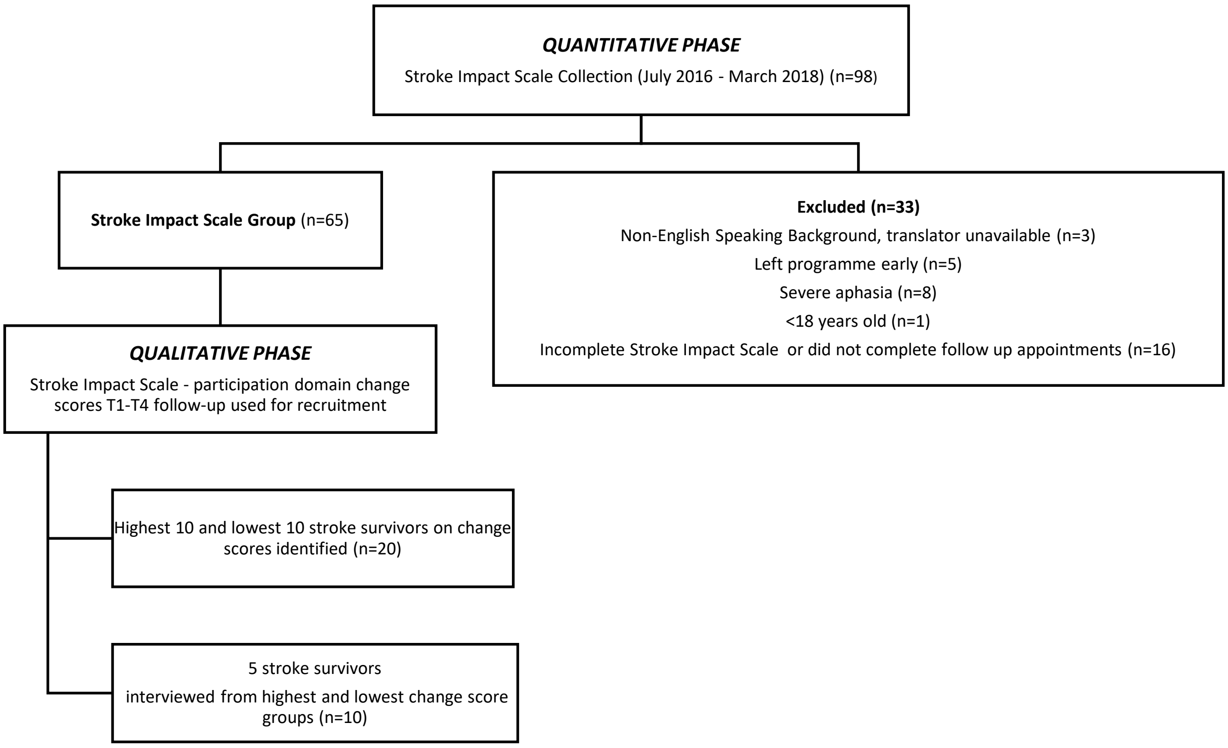

Figure 1. Participant flow sheet

Quantitative data analysis

Statistical analysis was conducted using Statistical Package for Social Sciences (SPSS) 24.0. To address our first question, we measured the Stroke Impact Scale 3.0[14], which is designed to assess multidimensional stroke outcomes for eight domains, and provide a summary score out of 100 for overall stroke recovery. A combined physical domain (Stroke Impact Scale- physical[15] is calculated by combining the domains of strength, mobility, activities of daily living (ADL)/instrumental activities of daily living (IADL) and hand function. Friedman's ANOVA tests were conducted to examine changes in each Stroke Impact Scale domain across all timepoints (T1-T4). Post-hoc tests were conducted using Wilcoxon tests with Bonferroni corrections (six time points) reported at the 0.0083 level of significance.

Our second question examined whether self-reported quality-of-life (Stroke Impact Scale) on admission influences response to intensive high dose upper limb rehabilitation. Here, response was assessed in terms of the International Classification of Functioning, Disability and Health (ICF) framework[16]; (i) 'activity' - upper limb activity levels (Action Research Arm Test, ARAT[17]), or (ii) 'participation' - Stroke Impact Scale-participation score. Multiple linear regression was performed (i) with six-month Action Research Arm Test as the dependent variable, individual admission Stroke Impact Scale scores and age as the independent variables, whilst also correcting for admission Action Research Arm Test. (ii) With six-month participation as the dependent variable, individual Stroke Impact Scale admission scores, age and admission Action Research Arm Test as independent variables, whilst correcting for admission participation scores.

Finally, Stroke Impact Scale-participation change scores were determined from T1 to T4 to identify the individuals with highest and lowest change scores. These were used for recruitment for the qualitative phase addressing research question three.

Qualitative Topic Guide

Supplemental Box 1 presents the interview topic guide. The interviews aimed to explore participants' perspectives on their illness and sense of control over their upper limb recovery, as well as how these factors influenced their social participation and quality of life, providing context to the quantitative data. The interview topic guide reflected previously published research using the Revised Illness Perceptions Questionnaire[18], the Stroke Self-Efficacy Questionnaire[19] and Leventhal's Common Sense Model of Self-Regulation[20] as conceptual models.

A group of four specialist neurological physiotherapists and occupational therapists appraised the topic guide, and it was piloted with three stroke survivors prior to use in the interviews.

Qualitative procedure and data analysis

Semi-structured interviews were conducted in person or over the phone by the first researcher (AS). In-person interviews were completed with mild to moderate aphasic participants using supported conversation techniques such as using one written question per page and bolding key concepts, as well as allowing additional time for response. The topic guide focused data collection in the interviews by using open questions and generic prompts to allow participants to express their own experiences and perceptions. Each interview was digitally audio-recorded, and complementary field notes were taken. All interviews were transcribed verbatim.

Qualitative data were analysed inductively using thematic analysis described by Braun and Clarke.[21] The first researcher (AS) independently read the complete data set within the higher-change (Group 1) and lower-change (Group 2) group, then went through the de-identified transcripts to identify topics of interest and generate initial codes. Similarities and differences in the two interview groups were noted during coding. The transcripts were read, considered and coded by a second researcher (FB) and two further authors (JF, MH) were consulted for quality assurance. The credibility of the thematic analysis and theme development was strengthened through repeated discussions during the analysis, multiple transcript reviews, and interpretation by two researchers (AS, FB). A research team meeting was convened with the wider research team (AS,FB,JF,MH) for robustness and to develop final themes. A reflective diary was used by the first researcher during recruitment, interviews and data analysis. Please see COREQ checklist in Supplementary Table 1.

Results

Patient characteristics

Characteristics of the Stroke Impact Scale sample (n=65) and the excluded participants (n=33) of the programme (July 2016 to March 2018) are shown in Table 1. No statistically significant differences can be found between the Stroke Impact Scale sample, and those excluded.

Table 1. Characteristics of stroke survivors on admission

	SIS study sample (n=65)	Excluded sample (n=33)	Comparison tests
Age (years)			
Median (IQR)	55 (46-60)	52 (43-61)	p=0.80
Gender			
Female (n, %)	25 (38.5%)	8 (24.2%)	p=0.18
Male (n, %)	40 (61.5%)	25 (75.8%)	
Affected Upper Limb			
Right (n, %)	29 (44.6%)	14 (42.4%)	p=1.0
Left (n, %)	36 (55.4%)	19 (57.6%)	
Time since stroke (months)			
Median (IQR)	15 (7–35)	22 (11-41)	p=0.37
HADS (total)			
Median (IQR)	12.5 (9.7-16.0)	14.5 (8.0- 19.3)	p=0.58
Neurological Fatigue Index			
Median (IQR)	38 (30-44)	39 (33-44)	p=0.54
Modified Barthel Index (/20)			
Median (IQR)	19 (18-19)	18 (16-19)	p=0.17
ARAT (/57)			
Median (IQR)	21(7-39.5)	15(8.5-36.5)	p=0.97

Difference in medians tested with Mann-Whitney test. Difference in proportions was tested with χ^2 test.
SIS, Stroke Impact Scale; HADS, Hospital Anxiety and Depression Scale; ARAT, Action Research Arm Test.

a) Changes in self-reported quality-of-life after intensive high dose upper limb rehabilitation

Each Stroke Impact Scale domain showed statistically significant changes over time (Table 2 and Figure 2,3) for strength ($\chi^2(3)=29.09$, $p<0.001$); ADL/IADL ($\chi^2(3)=50.53$, $p<0.001$); hand function (χ^2 $(3)=53.93$, $p<0.001$); mobility ($\chi^2(3)=25.47$, $p<0.001$); memory and thinking ($\chi^2(3)=8.65$, $p=0.034$); communication ($\chi^2(3)=12.17$; $p=0.007$); emotion ($\chi^2(3)=25.21$; $p<0.001$); participation ($\chi^2(3)=23.01$, $p<0.001$); overall recovery ($\chi^2(3)=60.24$, $p<0.001$). The combined physical score also changed significantly over time ($\chi^2(3)=57.97$, $p<0.001$). In addition, participation in the programme was associated with an increase in Action Research Arm Test scores over time ($\chi^2(3)=86.32$; $p<0.001$) (Table 2 and Figure 4). Post-hoc analysis and significance of changes in outcome measures between each time point are shown in Supplementary Table 2.

On average, clinically meaningful improvements occurred from admission to discharge (Stroke Impact Scale: strength, ADL/IADL, mobility, arm and Action Research Arm Test), admission to 6-week follow up (Stroke Impact Scale: strength, ADL/IADL, mobility and Action Research Arm Test) and admission to 6-month follow up (Stroke Impact Scale: ADL/IADL, mobility, arm and Action Research Arm Test). See Supplementary Table 3 for percentage of individuals who exceeded minimal clinically important differences at each timepoint.

Table 2. Descriptors of Action Research Arm Test and Stroke Impact Scale domains

ICF Domain	Outcome Measure	Domain	Admission	Discharge	6-weeks	6-months
			T1	T2	T3	T4
Activity	ARAT		21 (7 - 39.5)	28 (10.5 – 46)	28 (10 – 45.5)	27 (10.5 – 49.5)
Participation	SIS	Strength	50 (34.9 – 62.5)	62.5 (50 – 75)	62.5 (50 – 71.9)	62.5 (46.9 – 75)
		Memory	85.7 (73.2 – 100)	92.9 (78.6 – 96.4)	92.9 (78.6 – 100)	92.9 (78.6 – 100)
		Emotion	75 (61.1 – 87.5)	86.1 (75 – 91.7)	80.6 (69.4 – 88.9)	80.6 (63.9 – 91.7)
		Communication	96.4 (78.6 – 100)	96.4 (89.3 – 100)	100 (85.7 – 100)	96.4 (85.7 – 100)
		Activities of daily living	62.5 (52.5 – 75)	75 (60 – 86.3)	72.5 (60 – 87.5)	72.5 (61.3 – 85)
		Mobility	77.8 (70.8 – 88.9)	86.1 (75 – 97.2)	86.1 (69.4 – 95.8)	83.3 (72.2 – 91.7)
		Hand function	20 (5 – 45)	50 (15- 72.5)	40 (20 – 70)	50 (17.5 – 77.5)
		Participation	53.1 (34.4 – 68.8)	68.75 (48.4 – 79.7)	65.6 (50 – 81.3)	59.4 (45.3 – 87.5)
		Recovery	50 (42.5 – 65)	65 (50- 75)	65 (52.5 – 75)	70 (50 – 78)

All scores given as median (IQR). ARAT, Action Research Arm Test; SIS, Stroke Impact Scale

[Insert Figure 2a-e]

Figure 2. Graphical representation of Stroke Impact Scale physical domains: (a) combined physical score (b) strength, (c) ADL's/IADL's, (d) arm (e) mobility. Each data point represents a single patient showing individual scores at admission, discharge, 6-weeks and 6-months after discharge. Median and upper and lower quartiles are shown. ADLs, Activities of Daily Living.

[Insert Figure 3a-e]

Figure 3. Graphical representation of Stroke Impact Scale non-physical domains: (a) overall recovery score (b) communication, (c) memory and thinking, (d) emotion, (e) participation. Each data point represents a single patient showing individual scores at admission, discharge, 6-weeks and 6-months after discharge. Median and upper and lower quartiles are shown.

[Insert Figure 4]

Figure 4. Graphical representation of Action Research Arm Test scores at each time point. Each data point represents a single patient, showing individual scores at admission, discharge, 6-weeks and 6-months after discharge. Median (solid line) and upper and lower quartiles (lighter lines) are shown. ARAT, Action Research Arm Test.

b) The influence of self-reported quality-of-life on admission on activity and participation after intensive high dose upper limb rehabilitation

After controlling for Action Research Arm Test at admission, none of the individual Stroke Impact Scale admission scores helped to explain six-month Action Research Arm Test scores. The overall linear regression model was significant and explained 87.6% of the variance in Action Research Arm Test scores (six- month) (F(8,56)=57.56, *p*<0.001; adj. R-square = 0.876, SE 6.77). Further details in Table 3 below.

Table 3. Admission Stroke Impact Scale and Action Research Arm Test scores in relation to 6-months Action Research Arm Test scores

Variables Entered	B	S.E. of B	βeta	t	*p*-value
Constant	10.28	6.43		1.60	0.12
ARAT Admission	0.97	0.05	0.90	18.45	0.00
Age	-0.01	0.07	-0.01	-0.17	0.87
SIS Physical Admission	0.07	0.08	0.05	0.85	0.40
SIS Memory Admission	-0.12	0.08	-0.11	-1.53	0.13
SIS Emotion Admission	-0.04	0.06	-0.03	-0.63	0.53
SIS Communication Admission	0.02	0.06	0.02	0.36	0.72

SIS Participation Admission	-0.01	0.05	-0.01	-0.08	0.94
SIS Overall Recovery Admission	0.08	0.05	0.07	1.40	0.17

B : unstandardised coefficient βeta: standardised coefficient Dependent Variable: ARAT T4 (6-months)
SIS, Stroke Impact Scale; ARAT, Action Research Arm Test.

After controlling for admission Stroke Impact Scale-participation scores; memory and overall recovery on admission explained 31.1% of the variance in participation scores at six-month follow-up. The final linear regression model was significant (F(8,56)=4.606, *p*<0.001; adj. R-square = 0.311, SE 19.98). Further details in Table 4 below.

Table 4. Admission Stroke Impact Scale and Action Research Arm Test scores in relation to participation at 6 -months

Variables Entered	B	S.E. of B	βeta	t	*p*-value
Constant	-7.94	18.97		-0.42	0.68
Age	-0.06	0.21	-0.03	-0.29	0.77
SIS Physical Admission	-0.44	0.24	-0.27	-1.83	0.07
SIS Memory Admission	0.60	0.22	0.46	2.72	0.01
SIS Emotion Admission	0.06	0.17	0.04	0.32	0.75
SIS Communication Admission	-0.06	0.19	-0.05	-0.30	0.76
SIS Participation Admission	0.37	0.13	0.35	2.82	0.01
SIS Overall Recovery Admission	0.44	0.17	0.32	2.61	0.01
ARAT Admission	0.28	0.16	0.20	1.77	0.08

B : unstandardised coefficient βeta: standardised coefficient Dependent Variable: SIS-participation 6-months
SIS, Stroke Impact Scale; ARAT, Action Research Arm Test.

c) Qualitative Phase Findings

Semi-structured interviews were conducted with ten participants out of 14 approached. Their characteristics are presented in Table 5 below. Comparison of clinical diagnosis of individual anxiety and depression scores showed there were more participants with mild and moderate symptoms within the lower-change group. The higher-change group (Group 1), demonstrated an average change of participation scores from admission to six-month follow-up of +46.3 (40.6 to 62.5) (out of 100). The lower-change group (Group 2) demonstrated an average change of -29.4 (-25.0 to -34.4). This reveals a large difference in participation change scores, with no overlap between the two interviewed groups. Mean interview duration was 47 minutes.

Table 5. Interview participant characteristics

Participant No	Group	Age	Gender	Time since stroke (months)	ARAT (T1) /57	ARAT (T4) /57	HADS (Depression)	HADS (Anxiety)	Clinical HADS diagnosis [22]
1040	1	35	M	16	7	9	7	4	Normal
1032	1	47	F	7	53	57	8	5	Mild depression
1002	1	58	M	46	32	37	3	2	Normal
1003	1	36	F	133	25	40	0	0	Normal
1013	1	38	M	15	7	13	5	9	Mild Anxiety
1006	2	19	F	100	9	12	8	5	Mild depression
1034	2	62	F	29	40	40	6	3	Normal
1027	2	47	F	6	23	30	10	14	Moderate anxiety and depression
1001	2	53	M	22	22	28	14	9	Moderate depression and mild anxiety
1057	2	47	M	14	7	7	8	3	Mild depression

HADS, Hospital Anxiety and Depression Scale; ARAT, Action Research Arm Test.

Themes

Group 1 had five main themes with subthemes; Group 2 had six themes with subthemes identified. The qualitative data triangulates with the quantitative data and demonstrates interrelated but divergent views between groups in four shared themes. Group 1 described more positive views and influences alongside the individual theme of ‘getting on with life’. Group 2 on the other hand, described more negative perspectives and influencing psychosocial factors on their recovery and social participation, including themes of ‘hidden negative effects’ and ‘loneliness’. Findings are presented in Table 6.

Although an inductive approach was used in the thematic analysis, we mapped the themes back to the Revised Illness Perception Questionnaire[18] and Common-Sense Model of Self-Regulation[20] structure in Supplementary Table 4. This aimed to provide an explanatory approach to how the two groups differed in their psychosocial outcomes and coping processes.

Table 6. Summary of themes and quotes identified by stroke survivors in Group 1 and 2

Group 1		Group 2	
Main Theme	Quotes	Main Theme	Quotes
BELIEFS ABOUT RECOVERY ***Optimism moderated by realism*** Subthemes • Realistic expectations • Keeping open to recovery	*“I expected it to take a year or so but from back then to today, you know I am still affected by the stroke. So, I don’t know when the stroke will…the recovery will actually take place, or if there ever is recovery.”* (1013) *“So, my recovery’s fairly constant…I haven't really had any times where I thought it hasn’t, it’s not improving or anything like that, so it’s quite good really.”* (1040) *“Yes, your mind has to think you can – even though you don’t know, you really don’t know. You have to think that you can recover.”* (1032)	BELIEFS ABOUT RECOVERY ***‘I don’t think it’s going to get any better’*** Subthemes • Negative recovery expectations and perceptions • Poor coping and adjustment • Reliance on health professionals	*“I don’t think it’s going to get any better, I cannot see any improvement”* (1034) *“I just feel that everything that can be done has been done for me. It’s just learning to live with it now, but that’s very difficult.”* (1001) *“I’m still very upset about it, I still don’t cope with it very well.”* (1001) *“Having input and having people telling you- I know you’re supposed to do it by yourself- but I think it’s really important to have someone there going, you need to do this if you want to get better.”* (1006)
ALTERED ROLES, VALUES AND IDENTITY ***‘There are more important things’*** Subthemes • Change • Purpose	*“After stroke, after two months I start going back to uni already, although I’m paralysed, you can still use your brain.”* (1032) *“What is apparent to me is I had a devastating event in my life, and I have been able to work despite it.”* (1013) *“It just makes you realise that there are more important things too, than money and looking good.”* (1040)	ALTERED ROLES, VALUES AND IDENTITY ***‘You’re not the same person’***	*“People want to see you as the same person, and you're just not, for lots of things. And I think, as I'm sitting here, if you had me on a, pictures of me, do I look any different? I sit on the train sometimes; do I look different?”* (1034) *“Just the way I feel, really, I don’t feel like me. I was quite an outgoing person, and always on the go and everything, and it sort of stopped me in my tracks.”* (1001)
THE MOTIVATION PUZZLE ***‘Where I want to be’***	*“I try, I try everything. All the exercises, like a dog, you know you’re learning like a dog…Everything I can do, I do it.”* (1032) *“I don’t believe in difficulties. I believe in solutions. Difficult things, it stops people from doing things they wanna do. Solutions help them, help me…be where I want to be. And now I want to step twenty steps forward, you know, so yes to do that I’ve got to go through a lot of*	THE MOTIVATION PUZZLE ***‘Don’t have the motivation’***	*“I know that I could if I worked really hard at it, but I also know that I’ve got other stuff going on, and I don’t really have the time to do that.”* (1006) *“Yeah, so I had the stroke and then I sourced it and realised OK, while you’re sitting at home, not allowed to drive, not allowed to do this, that and the other, maybe you can get into that, so I did.”* (1027)

	things, but those things are all minor compared to where I want to be." (1003)		
NEGOTIATING CONFIDENCE AND INDEPENDENCE *'No way to put a number to how confident I feel'*	*"Well I feel as if I'm in control of the recovery completely, when it happened, when it first happened, I didn't feel any control over anything even over my life."* (1040) *"I try very much to get things done myself.., I kind of know my limitations. But to as much extent as possible I do things myself."* (1013) *"Before this my sister was always there but I think she had done enough, I have to get on with it."* (1002*)*	NEGOTIATING CONFIDENCE AND INDEPENDENCE *'I'm a massive burden'* Subthemes • Dependence on family • Accessing peer support	*"I feel that I'm so dependent on my husband, and friends and family. They don't seem to mind, but I mind."* (1034) *"Yes yes. But I think (wife) is good, is very, very good. (Wife) tired, 2 years….Yes but Pilates, kids, me."* (1057) *"No, I haven't had any other treatments, nothing else has been offered for me to take up or look into, apart from meeting with other stroke survivors in the area. "* (1027)
'Getting on with life'	*"You know it's more like. It's easier for me to forget the life I had before my stroke and consider the stroke as a starting point. And where I am now in respect to where I was (date of stroke), I find that easier. I think that's the better way to look at it."* (1013) *"Just getting out and I think just general things in life, going on that bus on my own, even just a small journey and I'll go on here. "* (1002) *"I was quite angry at the start but after about a year I suppose, I just sort of sucked it up and embraced it really, it's just, the way I see it it's just one of those things that's sent to try you and test you."* (1040) *"I've experienced a lot of things, you know that now I just chose not to speak about them, you know. I just chose to move forward, because that is what life is about, you know. Life is all about moving forwards, because every second counts, in life you know."* (1003)	***Hidden negative effects***	*"I also have cognitive difficulties, so short-term memory loss… and spatial awareness problems, other things, and extreme fatigue. I think that's a massive problem with people who've had strokes, is because it's a hidden effect is the fatigue, and also depression and anxiety."* (1006) *"I thought, I don't want to go down that road where I'm taking medication for depression, so …I just talked to my children about it, but not really to the GP, because I didn't want to be labelled."* (1027) *"Eight months, lower, lower, lower – I think that below the barrel. Then the pill, up, up, up."* (1057)
		Loneliness	*"I've tried to explain the sensations that I've got with it, but nobody, nobody, not even my husband, who is my closest, understands how bad it is."* (1034) *"I would say it's quite boring because having the stroke has limited me" (1034)* *"I haven't got much of a life really"* (1001)

Theme 1 – Beliefs about recovery

Group 1 participants described a realistic approach to recovery with an understanding that their initial expectations of recovery were probably incorrect. Although uncertain about future recovery they acknowledged slow ongoing improvements, emphasised the importance of positive thinking and optimism about future recovery, as well as recognising barriers to recovery.

In contrast, Group 2 participants debated their unrealistic initial expectations of recovery with participants expressing difficulty with coping, showing limited acceptance and control over their stroke and recovery. There was a clear focus on ‘being abandoned’ and a lack of support and services by health professionals, with participants relying on ongoing support, motivation and guidance for recovery.

Theme 2 – Altered roles, values and identity

All participants noted life changes since their stroke. Group 1 especially emphasised shifts in identity and purpose during recovery, highlighting positive changes in roles, values, and self-perception. In order to reconstruct their identity, all participants in Group 1 had found ways to adapt, adjust, or return to their salient roles and tasks.

Group 2 viewed the changes in their identity in an opposing way; describing a loss of confidence in themselves and their abilities. There was discontinuity between ‘them’ before and now, with more focus on not being themselves or the loss of a part of them, and uncertainty about their new identity or ability to participate in roles.

Theme 3 – The motivation puzzle

Group 1 consistently identified that internal motivation and motivation from others in terms of support was a crucial part of recovery and social participation. Their self-motivation and determination indicated a desire to try to move forwards and take responsibility for their own learning and recovery.

Conversely, Group 2 participants described a lack of internal motivation and self-regulation, with reference to a lack of time and professional support as barriers to improvement or moving forwards.

Theme 4 - Negotiating confidence and independence

Group 1 highlighted the progression of their confidence over time, and the dynamic process of regaining control of their recovery and lives. They indicated that regaining confidence and independence was a key ingredient impacting on social participation and that a reduced reliance on others was important in getting their confidence and autonomy back.

Group 2 constructed their independence in the opposite way, as reliance and dependence on others, expressing a felt lack of control and reliance and dependence on family members. The participants appeared to have an inherent feeling of guilt because of this reliance and burden on family, with an anger or frustration with not having professional support.

Theme 5 - Hidden negative effects (Group 2 only)

Group 2 identified invisible aspects of stroke that impact their recovery, coping and participation in day to day life such as pain, fatigue and depression. For the most part, participants had accessed support or treatment for mood disorders such as anti-depressants or counselling, but there was general uncertainty on how to manage these hidden symptoms.

Theme 6 – Loneliness (Group 2 only)

Participants in Group 2 described feelings of boredom, loneliness and isolation with quotes reflecting the experiences of stroke survivors who feel restricted, and uncertain about their path forward.

Theme 7 - Getting on with life (Group 1 only)

All Group 1 participants spoke of the intense emotions associated with having a stroke and the challenge of adjustment, but demonstrated an active decision to focus on their abilities and get on with life. Adjustment, rather than acceptance, was crucial for recovery and ongoing social participation.

Discussion

The study findings indicate that in this cohort of stroke survivors, all participants improved in several components of self-reported quality-of-life following participation in Queen Square Upper Limb programme. We found significant improvements in the Action Research Arm Test (measure of activity) from admission to all time points and all physical domains of the Stroke Impact Scale from admission to discharge. With exception of the mobility domain, improvements were maintained at six-weeks, with a trend for maintenance at six-months. Interestingly, other studies investigating upper limb treatment do not report all Stroke Impact Scale domains,[23,24] although the EXCITE[25] trial, (a two-week programme of constraint-induced movement therapy early after stroke) reported improvements in the Stroke Impact Scale-hand function but no change in Stroke Impact Scale domains not directly related to paretic upper limb function.

In this sample, in general, most stroke survivors reported improvements in self-rated participation and overall recovery scores, suggesting greater engagement in everyday life. Interestingly, the non-physical SIS-domain of emotion improved from admission to discharge but then reduced from discharge to six-month follow-up. Several research studies have indicated that engaging in physical training may yield beneficial effects on non-physical outcomes like depression and anxiety.[26,27] Additionally, the initial improvement in self-rated emotion in our study may be explained, in part, by the attention effect of treatment[28], enriched environment[29] and therapeutic relationship[30] developed during the programme. The subsequent reduction in emotion scores is perhaps not surprising as these positive elements are lost and stroke survivors are then expected to self-manage their ongoing recovery with 'check-ins' only at six-week and six-months. Depression and anxiety affect approximately one-third of stroke survivors[31] and in our post-hoc analysis, we observed a greater reduction in emotion scores from discharge to the six-month follow-up among individuals with higher levels of anxiety and depression at admission (Spearman's rho(62) = -0.28, p = 0.028).

In our study, the quantitative results converged with the qualitative results, with alignment between the Stroke Impact Scale domains of emotion and recovery and the psychosocial themes derived. Although similar in levels of upper limb activity, there were clear contrasts between the groups with differences in the positive valence compared to negative valence in the themes. When considering the Common-Sense Model[20] and how stroke survivors perceive their illness, the higher-change group acknowledged changes in their identity and values, while being more realistic about their uncertain illness consequences and timeline. They expressed optimism about the possibility of further improvements or changes, aligning with the concept of 'keeping the door open' described by Barker and Brauer.[32]

Individuals in the lower-change group held more pessimistic views about the possibility of recovery and viewed the impact of their illness as more severe. These individuals felt they had limited control over their stroke and recovery, and rather than taking an active role in their rehabilitation, they appeared to be more passive recipients of information and treatment and believed they required ongoing professional support, which aligns with findings in other studies.[4,5,33] This contrasts with the proactive self-management approach promoted by the Queen Square Upper Limb programme. The highlighted hidden effects of stroke in this group also emphasise the intricacy of rehabilitation, where considerations extend beyond physical functioning to encompass fatigue, pain, emotional and cognitive well-being; all crucial elements to take into account when devising rehabilitation programmes, even targeted ones, considering the disciplines and skillsets that can provide an optimal service.

One limitation of our study is that the data are from a clinical service which has no control group. However, our participants are chronic stroke survivors who are generally not expected to change much without ongoing rehabilitation, as shown by historical control groups[34]. Although our design is retrospective, we are taking advantage of a rich data set that was collected as part of the Queen Square Programme to support diverse research aims, including those addressed here. While valuable, the exploratory design, limited sample size, and absence of a control group restrict the generalisability of the findings. Our cohort is also sampled from those considered likely to benefit from Queen Square Upper Limb Programme, therefore stroke survivors who are very dependent with severe physical, cognitive, or functional impairments may be less represented, although the range of upper limb impairments is wide[11]. This study also excluded those with severe communication difficulties, non-English speakers, and individuals who did not complete measures at each timepoint. Additionally, as interview participants were recruited using a purposive sampling method from one site, it must be considered that extraneous factors may have influenced outcomes and perspectives. Finally, the interviewer (AS) is a physiotherapist with clinical experience in the programme, which may have influenced responses and openness during interviews. Her professional background could also have influenced the thematic analysis and interpretation of the qualitative data.

In conclusion, this mixed methods study is the first to report on the multi-dimensional aspects of quality-of-life following an intensive upper limb neurorehabilitation programme. Upper limb recovery could be a significant contributor to stroke survivors regaining function, allowing participation in meaningful activities, social and life roles. Emotional and psychosocial factors impacted on quality-of-life outcomes and recovery in both the study components, therefore consideration should be given to support requirements for those with higher psychosocial needs for development and maintenance of upper limb recovery, social participation and quality-of-life.

With no universally accepted clinical protocol for upper limb rehabilitation following stroke, and varying treatment programmes, duration, intensity, and frequency of therapy, individualisation to both physical and psychosocial needs is fundamental. Understanding how different treatments affect a range of outcome measures will help us understand how to combine them to help stroke survivors the most. This aligns with the broader view that rehabilitation is a complex intervention requiring the integration of interconnected elements to address the holistic needs of stroke survivors.[35] Further research is justified using a similar intervention with utilisation of a larger sample size and a control group.

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Statements and Declarations

Ethical considerations

The quantitative phase of the study was regarded as a service evaluation and approval was gained from City, University of London Research Ethics Committee (reference no MRes/17-18/15). Ethical approval was granted in full from NHS Research Ethics Committee (reference no 18/NE/0101) for the qualitative phase of the study. University College London Hospitals (UCLH) NHS Trust Research and Development approval was also obtained for both phases of the study.

Consent to participate

The participants in the qualitative phase voluntarily signed a consent form before being recruited for interview. This included written informed consent to conduct the interviews and publish the anonymised data in the study.

Consent for publication

Not applicable.

Declaration of conflicting interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Author Contributions

Contribution to the conception and design (ALL); contribution to the acquisition of data, or analysis and interpretation of data (AS, JF, MH, NW, FB); drafting the article or revising it critically for important intellectual content (AS, JF, MH, NW); final approval of the version to be published (ALL).

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Data availability

Anonymised data supporting this study are available from the corresponding author upon reasonable request.

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