



Schnabel, S. et al. (2020) Experiences of augmented arm rehabilitation including supported self-management after stroke: a qualitative investigation. *Clinical Rehabilitation*, (Accepted for Publication)

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/222508/>

Deposited on 21 August 2020

Enlighten – Research publications by members of the University of Glasgow  
<http://eprints.gla.ac.uk>

## Clinical Rehabilitation

### Experiences of augmented arm rehabilitation including supported self-management after stroke: a qualitative investigation

Journal:	<i>Clinical Rehabilitation</i>
Manuscript ID	CRE-2020-9582.R1
Manuscript Type:	Original Article
Date Submitted by the Author:	07-Aug-2020
Complete List of Authors:	Schnabel, Stefanie; Glasgow Caledonian University, School for Health and Life Sciences; Glasgow Caledonian University van Wijck, Frederike; Glasgow Caledonian University, Institute for Applied Health Research Bain, Brenda; Glasgow Caledonian University, Centre for Living, School for Health and Life Sciences Barber, Mark; NHS Lanarkshire, Medicine for the Elderly and Stroke Dall, Philippa; Glasgow Caledonian University, Centre for Living, School for Health and Life Sciences Fleming, Alexander; Different Strokes, Different Strokes Central Services Kerr, Andrew; University of Strathclyde, Biomedical Engineering Langhorne, Peter; Glasgow Royal Infirmary, Geriatric Medicine McConnachie, Alex; University of Glasgow, Robertson Centre for Biostatistics Molloy, Kathleen; Different Strokes, Different Strokes Central Services Stanley, Bethany; University of Glasgow, Robertson Centre for Biostatistics Young, Heather; Glasgow Caledonian University, Centre for Living, School for Health and Life Sciences Kidd, Lisa; University of Glasgow, Health and Wellbeing
Keywords:	Stroke, Upper extremity (arm), Exercise experience, Self-management, Normalisation Process Theory

SCHOLARONE™  
Manuscripts

## Abstract

*Objective:* To explore the experiences of stroke survivors and their carers of augmented arm rehabilitation including supported self-management in terms of its acceptability, appropriateness and relevance.

*Design:* A qualitative design, nested within a larger, multi-centre randomised controlled feasibility trial that compared augmented arm rehabilitation starting at three or nine weeks after stroke, with usual care. Semi-structured interviews were conducted with participants in both augmented arm rehabilitation groups. Normalisation Process Theory was used to inform the topic guide and map the findings. Framework analysis was applied.

*Setting:* Interviews were conducted in stroke survivors' homes, at Glasgow Caledonian University and in hospital.

*Participants:* 17 stroke survivors and five carers were interviewed after completion of augmented arm rehabilitation.

*Intervention:* Evidence-based augmented arm rehabilitation (27 additional hours over six weeks), including therapist-led sessions and supported self-management.

*Results:* Three main themes were identified: (1) acceptability of the intervention (2) supported self-management and (3) coping with the intervention. All stroke survivors coped well with the intensity of the augmented arm rehabilitation programme. The majority of stroke survivors engaged in supported self-management and implemented activities into their daily routine. However, the findings suggest that some stroke survivors (male >70 years) had difficulties with self-management, needing a higher level of support.

*Conclusion:* Augmented arm rehabilitation commencing within nine weeks post stroke was reported to be well tolerated. The findings suggested that supported self-management seemed acceptable and appropriate to those who saw the relevance of the rehabilitation activities for their daily lives, and embedded them into their daily routines.

## 1 Introduction

2 Stroke is a leading global health problem and a major cause of disability in adult life.<sup>1</sup> It is  
3 estimated that arm impairment affects over 70% of acute stroke survivors,<sup>2</sup> half of whom  
4 still have reduced arm function at six months post stroke.<sup>3</sup> This has an impact on activities of  
5 daily living, well-being and health-related quality of life.<sup>4</sup> Arm function may be improved  
6 through repetitive, functional task practice, however the dose required (at least 20 hours  
7 more than usual care)<sup>5</sup> is difficult to deliver within existing health resources. Therefore,  
8 stroke survivors may need to engage in self-managed rehabilitation.

9 Self-management has been adopted by UK national clinical guidelines for stroke.<sup>6</sup> A  
10 qualitative study which investigated the factors influencing self-management after stroke  
11 found that *support* for self-management was crucial including the following key features:  
12 involvement of health care professionals, appropriate resources and the role of informal  
13 carers.<sup>7</sup> The idea of supported self-management in stroke and other chronic diseases is  
14 gaining prominence<sup>8</sup>, however little is known about the expectations and experiences of  
15 stroke survivors and their carers who engage in supported self-management as part of arm  
16 rehabilitation. Only one study has explored the experiences of stroke survivors of arm  
17 rehabilitation, using a non-immersive virtual reality system, in a clinical setting.<sup>9</sup> Stroke  
18 survivors were motivated to practise intensively, which was supervised by a therapist, and  
19 the overall experience was positive. However the acceptability of the intervention in terms  
20 of timing, dose, relevance and appropriateness was not explored.<sup>9</sup>

21 Supported self-management is also likely to confer a burden on patients and their  
22 carers.<sup>10,11</sup> Therefore, further investigation is needed into how best to support self-  
23 management and to minimise the treatment burden.<sup>8,11</sup> Normalisation Process Theory is  
24 concerned with the work people do to implement, embed and integrate new interventions  
25 into a daily routine,<sup>11, 12</sup> and has been applied to understand the work that stroke survivors  
26 do to implement and embed supported self-management.<sup>11</sup>

27 There is a particular need for more insight into how stroke survivors experience their  
28 engagement with rehabilitation in order to understand how their rehabilitation and self-  
29 management support needs can best be met.<sup>13</sup> Augmented arm rehabilitation after stroke is  
30 one area of stroke management which is prone to treatment burden, as more self-managed

1  
2  
3 31 treatment may be necessary to improve outcomes. This study aimed to explore the  
4 32 experiences of stroke survivors and their carers of an augmented arm rehabilitation  
5 33 programme including supported self-management, in terms of its acceptability,  
6 34 appropriateness and relevance.  
7  
8  
9

10  
11 35

## 14 36 **Methods**

17 37 This was a qualitative study. The COnsolidated criteria for Reporting Qualitative Research  
18 38 (COREQ)<sup>14</sup> standards were followed.

21 39 The study was conducted between March 2016 and October 2018. It was nested within the  
22 40 *Early VERSus Later Augmented Physiotherapy compared with usual upper limb*  
23 41 *physiotherapy (EVERLAP): a feasibility randomised controlled trial of arm function after*  
24 42 *stroke*. This was a mixed methods, randomised, multi-centre trial (Clinical Trial Registration  
25 43 number: ISRCTN 32522341).

31 44 Ethical approval was granted from the National Research Ethics Service (REC Reference  
32 45 14/WS/1136), NHS Research & Development departments and Glasgow Caledonian  
33 46 University's School of Health and Life Sciences Ethics Committee. The study was funded by  
34 47 the Charitable Trust of the Chartered Society of Physiotherapy (N/12/10) and the sponsor  
35 48 was Glasgow Caledonian University.

41 49 The EVERLAP study focused on exploring the feasibility of a definitive randomised controlled  
42 50 trial comparing Early and Later augmented arm rehabilitation with usual care. Information  
43 51 about the EVERLAP study is reported in detail elsewhere.<sup>15</sup> Briefly, stroke survivors were  
44 52 randomised into one of three groups; the Early group (starting augmented arm  
45 53 rehabilitation three weeks post stroke, together with usual care), the Later group (starting  
46 54 nine weeks post stroke, together with usual care) or the usual care only group. The content  
47 55 of the intervention comprised a manual of routinely available physiotherapy interventions,  
48 56 aimed at improving meaningful functional activity of the affected arm, based on current  
49 57 best evidence. This included treatment strategies for priming, augmenting and practising  
50 58 functional skills. Study physiotherapists formulated a patient-centred treatment plan for  
51 59 each participant, taking into account their needs, goals and abilities, current best evidence

1  
2  
3 60 and their clinical judgement. The target dose of augmented arm rehabilitation was an  
4  
5 61 additional 27 hours of arm rehabilitation (45 minutes each day, six days per week over six  
6  
7 62 weeks). These additional 27 hours included face-face time with the study physiotherapist, as  
8  
9 63 well as time undertaking supported self-management, with their proportion tailored to each  
10  
11 64 individual. Stroke survivors could choose between a booklet with activities or a mobile  
12  
13 65 phone reminder to supplement their supported self-management. The primary outcome  
14  
15 66 was the Action Research Arm Test at 24 weeks and a tool kit of secondary outcomes  
16  
17 67 included measures of impairment, activity limitation and participation restriction.<sup>15</sup> The aim  
18  
19 68 of this qualitative study was not to compare the Early and Later groups, but to explore the  
20  
21 69 experiences of participants in both these groups.

22  
23 70 All study participants gave written informed consent for their participation in an exit  
24  
25 71 interview after the end of the augmented arm rehabilitation programme to discuss their  
26  
27 72 experiences with a researcher, who was otherwise not involved in the study. The anonymity  
28  
29 73 of all stroke survivors and their carers was protected by using unique identification numbers  
30  
31 74 for all transcripts, and false names were given for publications and presentations.

32  
33 75 The inclusion criteria for this qualitative study followed the eligibility criteria for stroke  
34  
35 76 survivors and their carers (if available) in the EVERLAP study.<sup>15</sup> In addition, all stroke  
36  
37 77 survivors (including anyone with aphasia), who had completed the augmented arm  
38  
39 78 rehabilitation (from either the Early or Later group) and were willing to take part in an  
40  
41 79 interview were invited to this qualitative study. A convenience sampling approach was used.  
42  
43 80 Stroke survivors who had been part of the usual care group were not interviewed as the  
44  
45 81 purpose was to understand more about the acceptability of the augmented intervention.  
46  
47 82 Stroke survivors who did not complete the programme were not interviewed because it was  
48  
49 83 felt that it would not be appropriate to contact those who had withdrawn, as the most  
50  
51 84 common reason for withdrawal was being unwell or unwilling to continue.

52  
53 85 Stroke survivors and carers were approached by the study physiotherapist once they had  
54  
55 86 completed the EVERLAP intervention to arrange the interview. Interviewing stroke survivors  
56  
57 87 together with their carers was selected for several reasons: firstly, some carers played a role  
58  
59 88 in supported self-management. Also, carers could potentially add detail to what stroke  
60  
61 89 survivors did during their supported self-management, and add their perspective. Another

1  
2  
3 90 benefit of paired interviews is that they may complement one another in the storytelling  
4  
5 91 and the observation of non-verbal communication can add valuable insight.<sup>16</sup> Carers can  
6  
7 92 also be the voice for the participant in the interview when speech impairment is a  
8  
9 93 problem.<sup>17</sup> Carers who did not consent but were present during the interview were made  
10  
11 94 aware that their contributions were recorded and transcribed but could not be included in  
12  
13 95 the analysis of the findings.

14  
15 96 Semi-structured interviews with stroke survivors and their carers (if present) took place in  
16  
17 97 stroke survivors' homes, at the University, or in hospital, between September 2016 and April  
18  
19 98 2018 following a topic guide (Appendix 1). Interviews were audio recorded and transcribed  
20  
21 99 verbatim by a transcriber who was otherwise not involved in the study.

22  
23 100 The work of May et al.<sup>12</sup> and Murray et al.<sup>18</sup> was used to guide the application of  
24  
25 101 Normalisation Process Theory in this study. Normalisation Process Theory was used to  
26  
27 102 inform the topic guide and the analysis of the study findings.<sup>12,18</sup>

28  
29 103 The four main constructs of Normalisation Process Theory and how they were incorporated  
30  
31 104 into the topic guide for this study were as follow:

32  
33  
34 105 **Coherence (sense-making work):** Do stroke survivors and their carers understand the  
35  
36 106 condition and what can be done to manage the impact of their stroke?

37  
38 107 **Cognitive participation (relationship work):** Are stroke survivors and their carers engaged  
39  
40 108 and committed to the augmented arm rehabilitation programme and supported self-  
41  
42 109 management?

43  
44 110 **Collective action (enacting work):** Do stroke survivors and their carers make use of all  
45  
46 111 opportunities of the augmented arm rehabilitation programme? What is acceptable and  
47  
48 112 what is not acceptable to them?

49  
50 113 **Reflexive monitoring (appraisal work):** Do stroke survivors and their carers reflect on the  
51  
52 114 relevance and appropriateness of the augmented arm rehabilitation programme and how it  
53  
54 115 can be tailored to their needs?

55  
56  
57 116 The following areas were probed in relation to the constructs of Normalisation Process  
58  
59 117 Theory:

- 118 1) Life after stroke
- 119 2) Experience with the content, intensity, duration and timing of the augmented arm  
120 rehabilitation
- 121 3) Impact of the intervention on arm function
- 122 4) Relationship with the health professionals (study and usual care physiotherapists)
- 123 5) Impact of the intervention on quality of life
- 124 6) The role of the carer in the augmented arm rehabilitation programme.

125 The topic guide was piloted (the data were not included in the analysis) with two stroke  
126 survivors who were also involved in the design of the EVERLAP study. The topic guide was  
127 iteratively refined throughout the interview process to identify further areas for  
128 probing/discussion in subsequent interviews.

129 Data saturation was achieved after interview number 15 but two more interviews were  
130 conducted and no new data emerged. Interviews ranged in length between 16 min. and 71  
131 min. (median 39 min.).

132 During data collection and analysis a reflexive approach was adopted. Field notes were  
133 taken for each interview and used to supplement the data collection, to describe the  
134 context in which the interviews took place and the researchers' own feelings during field  
135 work.<sup>19</sup> The interviews were undertaken by two researchers, including the first author. As  
136 physiotherapists, both interviewers had experience working in the health service with stroke  
137 survivors. The interviewers were not directly involved in the recruitment to or the delivery  
138 of the EVERLAP intervention. The participants were aware that the interviewers were  
139 involved in the wider EVERLAP study and that the interviews were part of the first author's  
140 PhD study.

141 Framework analysis was used to analyse the transcripts<sup>20</sup>, which was regarded as the most  
142 appropriate approach because it provided a systematic structure to manage and interpret a  
143 rich data set. The transcripts were analysed according to the six steps of framework analysis:  
144 familiarisation, constructing an initial framework, indexing and sorting, reviewing data  
145 extracts, data summary and display, and description.<sup>20</sup> Data were managed using the  
146 software NVivo11. All identifiable data (names, places) were removed from the transcripts.  
147 Audio recordings were listened to, transcripts were read repeatedly and a coding framework



1  
2  
3 148 was established. The coding framework was further refined with each transcript read. For  
4  
5 149 each emerging theme a matrix was created which had several subthemes. The first author  
6  
7 150 and co-authors (chief investigator of the EVERLAP study (FvW) and experienced qualitative  
8  
9 151 researcher (LK)) were involved in the coding. Themes were discussed at different stages  
10  
11 152 during the process of analysis and final themes were agreed. During the abstraction and  
12  
13 153 interpretation stage, categories were developed and linkage between themes identified.<sup>20</sup>  
14  
15 154 Framework analysis was underpinned by the main principles of Normalisation Process  
16  
17 155 Theory, to which the findings were mapped.  
18  
19 156

## 21 157 **Results**

22  
23  
24 158 Stroke survivors were recruited for the EVERLAP study from six different hospitals in  
25  
26 159 Scotland.

27  
28  
29 160 A total of N = 39 stroke survivors (Early and Later group) and N = 10 carers (those who  
30  
31 161 consented) were eligible to take part in the interviews. N = 7 stroke survivors (N = 1 carer)  
32  
33 162 from the Early group and N = 10 stroke survivors (N = 4 carers) from the Later group took  
34  
35 163 part in the interviews. Therefore a total of 17 stroke survivors and five carers (those who  
36  
37 164 consented) were interviewed (six females, age range 40-84 years). The other stroke  
38  
39 165 survivors were interviewed alone or had carers present who did not consent. Three stroke  
40  
41 166 survivors with aphasia were interviewed, where only one carer was available for the  
42  
43 167 interview.

44  
45 168 A total of N = 22 were not available for the interview for the following reasons: N = 3 were  
46  
47 169 lost to follow-up, N = 10 discontinued with the intervention (including N = 5 who were not  
48  
49 170 well enough to continue, N = 3 who were not willing to continue, N = 1 died and N = 1 was  
50  
51 171 discharged to location outside catchment area) and N = 9 declined the interview (including  
52  
53 172 N = 2 who felt they had too much to cope with, N = 1 declined due to aphasia and N = 6 did  
54  
55 173 not give a reason).

56  
57 174 The demographics of stroke survivors who participated in the interviews are shown in Table  
58  
59 175 (1).  
60

1  
2  
3 1764  
5  
6 177 **[Table 1 about here]**7  
8  
9 178 The mean (SD) total amount of therapist-led augmented time per participant was 4h. 3 min.  
10 179 (2h. 44 min.) in the Early group and 5h. 16 min. (3h. 6 min.) in the Later group, which was  
11  
12 180 the maximum dose of face-face physiotherapist time that could be delivered.13  
14  
15 181 During the analysis, three main themes were identified: (1) acceptability of the intervention  
16 182 (2) supported self-management and (3) coping with the intervention. The following section  
17 183 presents the themes and subthemes and quotes from stroke survivors and carers. The  
18  
19 184 study findings were interpreted through the lens of Normalisation Process Theory. Table (2)  
20 185 gives an overview of how the subthemes align with the constructs of Normalisation Process  
21  
22 186 Theory. Carers of stroke survivors are referred to using the letter 'C' followed by their false  
23  
24 187 name. The Early and Later augmented therapy groups to which stroke survivors were  
25  
26 188 randomised are referred to using the letters 'EG' and 'LG' and followed by the age of the  
27  
28 189 participant (age not included for carers).29  
30  
31  
32 190 **[Table 2 about here]**33  
34  
35 19136  
37  
38 192 *Acceptability of the intervention*39  
40  
41 193 All stroke survivors and their carers felt positive about the augmented arm rehabilitation  
42 194 programme. All stroke survivors liked the intensity of the arm rehabilitation, the supportive  
43 195 nature of their interaction with the study physiotherapists, while the majority liked the  
44 196 opportunity to engage in supported self-management.45  
46  
47  
48  
49 197 Most stroke survivors reported that activities undertaken with the study physiotherapist  
50 198 and practised through supported self-management in their own homes were relevant to  
51 199 their daily lives and helped with managing the paresis and sensory impairment of the  
52 200 affected arm. The majority of stroke survivors said that the activities had a practical focus  
53 201 and regarded this as a positive aspect. Activities that were tailored to stroke survivors'  
54 202 needs and real-life activities that were meaningful to their daily lives, such as practising  
55 203 throwing a ball for people with small children or dogs, were perceived as being particularly

1  
2  
3 204 valuable. Stroke survivors also appreciated that the activities were built on what was done  
4  
5 205 the day before, challenging them a bit further. This is an example of *coherence* as well as  
6  
7 206 *cognitive participation*, where stroke survivors and their carers tried to improve their  
8  
9 207 understanding of the condition and engage in the management of the arm impairment after  
10  
11 208 stroke.

12  
13 209 *'... it [EVERLAP] was very much a practical focus for the exercises ... So that not*  
14  
15 210 *only was he doing the exercises but there was a purpose involved to perform the*  
16  
17 211 *exercises.'* (C of Timo, LG)

18  
19 212 For one stroke survivor the EVERLAP activities helped her to look after her young baby  
20  
21 213 again.

22  
23  
24 214 *'This month I have been looking after him [young son] myself so it [the strength]*  
25  
26 215 *is building up.'* (Lydia, EG, age 40 years)

27  
28 216 One of the stroke survivors however felt that the exercises were not optimally tailored to his  
29  
30 217 needs, reporting that:

31  
32  
33 218 *'More exercises for fine motor skills would have helped me more.'* (Peter, LG, age  
34  
35 219 64 years)

36  
37 220  
38  
39  
40 221 All stroke survivors valued the physiotherapist-led sessions and felt that the human contact  
41  
42 222 was vital because they needed someone to supervise the exercises, to give guidance and  
43  
44 223 support. The study physiotherapists also acted as a motivator to some stroke survivors and  
45  
46 224 others praised the supportive nature of their relationship. This aligns with the Normalisation  
47  
48 225 Process Theory construct *collective action*, which reflected on the opportunities created  
49  
50 226 through the augmented arm rehabilitation and finding out what is acceptable and not  
51  
52 227 acceptable to them as part of the therapist-led sessions.

53  
54 228 *'[The EVERLAP PT] was very very supportive and didn't em... even if you don't feel*  
55  
56 229 *like the exercising you know the EVERLAP PT is coming and em... it is good*  
57  
58 230 *em...she would just be very motivational.'* (Timo, LG, age 49 years)

1  
2  
3 231 *'So I suppose the human contact and the supportive relationship as I saw it was*  
4  
5 232 *important and helpful to me.'* (Peter, LG, age 64 years)  
6

7  
8 233 *'... the Study physiotherapist was a positive influence on me. When I was em ...*  
9  
10 234 *feeling down em ... she said like I am doing really well and stuff ... .'* (Lydia, EG,  
11  
12 235 age 40 years)  
13

14 236

15  
16  
17 237 All stroke survivors and their carers felt that the intensity of the EVERLAP intervention was  
18  
19 238 acceptable and well tolerated. Those stroke survivors and carers who engaged in supported  
20  
21 239 self-management reported that they coped well, implementing the 45 minutes of exercise  
22  
23 240 into their daily routine, and did not see it as a burden.  
24

25 241 *'The more the merrier. The intensity suits me.'* (Simon, LG age 65 years)  
26

27 242 *'Oh yeah it was good. It was intensive it really helped.'* (C of Simon, LG)  
28

29  
30 243 *'The more you can encourage people to do things the better.'* (Anthony, LG, age  
31  
32 244 56 years)  
33

34  
35 245 In terms of the duration of the EVERLAP programme, the views of the stroke survivors were  
36  
37 246 more variable. Several of the stroke survivors and their carers felt that six weeks of  
38  
39 247 augmented arm rehabilitation was sufficient as they felt that the study physiotherapists had  
40  
41 248 shown them most exercises and were not sure if a longer duration would have resulted in  
42  
43 249 any further improvements. Some reported that six weeks was not long enough and they  
44  
45 250 suggested that rehabilitation programmes should be extended to 12 weeks, as they needed  
46  
47 251 more direct support from therapists. Only one felt that the programme should have been a  
48  
49 252 bit shorter.

50 253 *'I think that was also the time to stop because I think any more em ...*  
51  
52 254 *improvements I am not sure if it would ... .'* *'I think it was perfect it was just*  
53  
54 255 *enough.'* (Timo, LG, age 49 years)  
55

56 256 *'... we did six weeks where we could have done with 12...you would em ... benefit*  
57  
58 257 *better the longer you got working with the likes of the study physiotherapist.'*  
59  
60 258 (Lewis, LG, age 75 years)

1  
2  
3 259 In terms of the timing of the EVERLAP programme, the views of the stroke survivors were  
4  
5 260 similarly divided. Most stroke from the Later group reported that it was ideal timing for  
6  
7 261 them, whereas some participants in this group reported that they would have liked to begin  
8  
9 262 earlier after their stroke. In the Early group, many felt that beginning the EVERLAP  
10  
11 263 programme early after their stroke had a positive impact on their recovery. This subtheme is  
12  
13 264 an example of *reflective monitoring* because stroke survivors and their carers reflected on  
14  
15 265 the intensity, duration and timing of the intervention and gave feedback on what could be  
16  
17 266 improved for a future study.

18  
19 267 *'I could have done with them earlier.'* (Thomas, LG, age 72 years)

20  
21 268 *'It kicked in at the right time. Because [Timo] had gained more strength.'* (C of  
22  
23 269 Timo, LG)

24  
25  
26 270

27  
28  
29 271 All stroke survivors felt that the EVERLAP programme had a positive impact on their life and  
30  
31 272 recovery after stroke. The augmented arm rehabilitation programme helped some stroke  
32  
33 273 survivors to set and achieve their personal objectives. It was also reported that the  
34  
35 274 intervention itself and the presence of the study physiotherapists had a positive impact on  
36  
37 275 mood and motivation. There were no negative aspects reported. This subtheme also mirrors  
38  
39 276 *reflective monitoring* as stroke survivors reflected on the relevance of the intervention to  
40  
41 277 their recovery.

42  
43 278 *'EVERLAP helped to set objectives. ... So it was good for me I think because the*  
44  
45 279 *danger ... would have been ... but get a bit lazy kind of thing and maybe sit too*  
46  
47 280 *much ... . I just felt there was positivity to it.* (Peter, EG, age 64 years)

48  
49 281 *'It's the mental attitudes and the knowledge of how to get better.'* (Sean, LG, age  
50  
51 282 68 years)

52  
53 283 *'I enjoyed them coming and I felt it was much more practical than anything I*  
54  
55 284 *received in the hospital ... maybe because they were in my house and they knew*  
56  
57 285 *what I was having to put up with.'* (Maureen, LG, age 72 years)

58  
59 286  
60

1  
2  
3 287 *Supported self-management*  
4  
5

6 288 Supported self-management practice that was encouraged as part of the therapist-led  
7  
8 289 sessions was reported to be valuable. It helped stroke survivors to feel in control of their  
9  
10 290 rehabilitation progress and provided a focus after discharge from

11  
12 291 *'... the very closed and supportive environment in the hospital ...'* (Peter, LG, age  
13  
14 292 64 years).  
15  
16

17 293  
18

19  
20 294 The majority of stroke survivors reported that they engaged in supported self-management  
21  
22 295 every day or most days and had established a routine for doing the exercises. They reported  
23  
24 296 on integrating supported self-management into a daily routine so that exercising did not  
25  
26 297 feel like a burden to them. However, three out of four stroke survivor participants who were  
27  
28 298 male and over the age of 70 reported that it was easier for them to engage in the exercises  
29  
30 299 when the study physiotherapist was present but that they did not do so when they were on  
31  
32 300 their own at home. Engagement in supported self-management aligns with *cognitive*  
33  
34 301 *participation* and showed how engaged and committed they were in this.

35 302 *'A [small] bit and often and I can feel the benefit. ... I don't like exercise[s] but I*  
36  
37 303 *have got to do it so I just try and build on it to achieve my daily routine.'* (Timo,  
38  
39 304 LG, age 49 years)  
40

41 305 *'But it [engaging in self-management] was basically a constant thing. ... it all*  
42  
43 306 *became part of my day.'* (Chris, LG, age 56 years)  
44  
45

46 307 However, some stroke survivors reported that they engaged in supported self-management  
47  
48 308 every couple of days, feeling that they did not cope with all the activities or the supported  
49  
50 309 self-management.

51  
52 310 *'I coped with some of them [exercises]. Some of them I couldn't do.'* (Simon, LG,  
53  
54 311 age 65 years)  
55  
56  
57  
58  
59  
60

1  
2  
3 312 *'I managed the exercises alright when the EVERLAP PT was there.'* *'All the*  
4  
5 313 *exercises were good at the time. But em ... well I am not doing them anymore and*  
6  
7 314 *em ... em ... and just nothing else is happening.'* (Lewis, LG, age 75 years)  
8  
9  
10 315

11  
12 316 Several stroke survivors reported that they were self-motivated to engage in exercises  
13  
14 317 themselves. Most motivation was related to specific goals such as acquiring better dexterity  
15  
16 318 or *'wanting to get better'* (Chris, LG, age 56 years) in general. Other motivators to engage in  
17  
18 319 supported self-management appeared to be a desire to return to work, caring  
19  
20 320 responsibilities for young families or for grandchildren. *Motivation for supported self-*  
21  
22 321 *management aligns with coherence* as stroke survivors and their carers understood what  
23  
24 322 can be done in rehabilitation to achieve their goals such as returning to work.  
25

26 323 These findings are illustrated by the following quotes:

27  
28 324 *'My hand and my brain are my tools of work so I need this [referring to hands and*  
29  
30 325 *brain] working ... I can't accept I'm not being able to write or type and that's how*  
31  
32 326 *I have to work on these. .... The self-motivation for me is to get back to work. ...*  
33  
34 327 *So I have got cars to pay, I have got a house to keep I have got a boy to put*  
35  
36 328 *through school and things like that. I need to get back to work and that's my*  
37  
38 329 *motivation.'* (Anthony, EG, age 56 years)  
39

40 330 *'I don't like exercises generally but I had a problem ... she [the EVERLAP PT] would*  
41  
42 331 *just be very motivational.'* (Timo, LG, age 49 years)  
43  
44

45 332 *'I practised as much as possible. I have always been that way I [cannot] sit and sit*  
46  
47 333 *and sit I have got to do something ... .'* (Ross, LG, age 63 years)  
48

49 334 *'Em ... looking after my son. Playing with him ... .So em ... I can take him [my son]*  
50  
51 335 *full time.'* (Lydia, EG, age 40 years)  
52

53 336

54  
55 337 Here, stroke survivors and their carers talked about the suitability of supported self-  
56  
57 338 management in addition to therapist-led sessions at that stage of their recovery. Most felt  
58  
59 339 that this was acceptable. A few stroke survivors felt overwhelmed with being asked to  
60

1  
2  
3 340 undertake exercises independently and wished for more therapist-led sessions as discussed  
4  
5 341 in the previous section. This is an example of *reflective monitoring* because stroke survivors  
6  
7 342 reflected on how appropriate supported self-management was at that point in time of their  
8  
9 343 rehabilitation and where modification was necessary such as needing more input from  
10  
11 344 therapists.

12  
13 345 *'So [yes] the more you can encourage people to do things the better. ... the*  
14  
15 346 *sooner you start these things the better.'* (Anthony, LG, age 56 years)

16  
17 347 *'If you don't do it [the exercises] you will stiffen up so it [the exercises] did help.'*  
18  
19 348 (Ross, LG, age 63 years)

20  
21  
22 349

23  
24  
25 350 It was often reported that tiredness, self-reported 'laziness', pain and other commitments  
26  
27 351 such as engaging with visitors or home helpers imposed barriers to supported self-  
28  
29 352 management. A facilitator for engaging in supported self-management was the exercise  
30  
31 353 booklet and the mobile phone reminder, which was offered to everyone in the study. The  
32  
33 354 majority used the exercises booklet and some (one from each of the Early and Later group)  
34  
35 355 used the mobile phone reminder. One user of the mobile phone reminder and his carer  
36  
37 356 reported that the reminder helped him considerably in doing the activities regularly. Others  
38  
39 357 felt they were motivated by the study physiotherapists to do the activities. Exercising was  
40  
41 358 reported as a motivation and a positive factor in their recovery after stroke. This subtheme  
42  
43 359 falls into the Normalisation Process Theory construct of *collective action* as stroke survivors  
44  
45 360 and their carers state what helped them most and what did not work in their rehabilitation.

46 361 *'Yes. Sometimes if there's fatigue you have just got to admit you know that that's*  
47  
48 362 *it today. Just make sure that you em ... it is not a case of em ... doing nothing it is*  
49  
50 363 *just even if I just do something ... . Some days you are good and some you are*  
51  
52 364 *not so good. ... visitors kind of wipe me out.'* (Timo, LG, age 49 years)

53  
54 365 *'Oh lots. Because with the phone, the phone was ideal because you could set it to,*  
55  
56 366 *you know, there is an alarm to go off, and that is what I did. So I put in em ... I*  
57  
58 367 *would select so many different exercises and then I did it for every hour didn't I?'*  
59  
60 368 (Anthony, LG, age 56 years)



1  
2  
3 369  
4  
5  
6 370 *Coping with the intervention*  
7  
8  
9 371 Stroke survivors and their carers talked about what helped them to commit to the demands  
10 372 of the augmented arm rehabilitation, such as undertaking supported self-management and  
11 373 decision-making.  
12  
13  
14  
15 374  
16  
17  
18 375 Several stroke survivors reported that they had a carer who was involved in their  
19 376 rehabilitation. The majority of those included said that their carers acted as a reminder and  
20 377 sometimes a controller for doing supported self-management. Most of the carers, who were  
21 378 available, were involved in the actual exercises such as helping with supporting the arm or  
22 379 monitoring the independent exercises. These findings show that the engagement and  
23 380 commitment of a support network is vital in the recovery after stroke, which is an example  
24 381 of *cognitive participation*.  
25  
26  
27  
28  
29  
30  
31 382 *'But we are getting there and I mean the support that he gets, even if he posts*  
32 383 *one of these wee videos the support he gets from TAE KWON DO, I think when he*  
33 384 *posted the first one you seen a lot of the people at TAE KWON DO didn't see him*  
34 385 *probably maybe the first month you were out of hospital you maybe weren't*  
35 386 *anywhere. But once I kind of got him to a class he would kind of walking with his*  
36 387 *feet and his stick and they were all "great to see you" and they were even*  
37 388 *mentioning as your hand was improving.'* (C of Anthony, LG)  
38  
39  
40  
41  
42  
43  
44  
45 389 *'Although as I said earlier on, sometimes I get lazy and my wife had to always*  
46 390 *remind me "have you done your exercises today" and would say "maybe or*  
47 391 *maybe not" [laughter].'* (Peter, LG, age 64 years)  
48  
49  
50  
51 392 *'Yes I help Timo once the study physiotherapist shows us what to do and she has*  
52 393 *advised me how far you can go. And which muscles can em ... .'* (C of Timo, LG)  
53  
54  
55  
56 394  
57  
58  
59  
60

1  
2  
3 395 Most stroke survivors reported that they were actively involved in the decision-making on  
4  
5 396 their goals and rehabilitation plan in relation to EVERLAP whilst others were happy to let the  
6  
7 397 study physiotherapists decide on the rehabilitation plan. *Being actively involved* aligns with  
8  
9 398 *coherence* because stroke survivors and carers need an understanding of the condition and  
10  
11 399 in the management of stroke in order to make decisions regarding their rehabilitation goals  
12  
13 400 and rehabilitation plan.

14  
15 401 *'I think the study physiotherapist was really good in seeing what I would need to*  
16  
17 402 *do more of.'* (Sean, LG, age 68 years)

18  
19 403 *'But with the study physiotherapists I was very much involved in what they were*  
20  
21 404 *doing. I am a control freak just so that you know I can't help it ... .'* (Maureen, LG,  
22  
23 405 age 72 years)

24  
25  
26 406

## 27 28 29 407 **Discussion**

30  
31 408 The findings from those who completed the programme and took part in the interview show  
32  
33 409 that the augmented arm rehabilitation within the EVERLAP study was acceptable, relevant  
34  
35 410 and meaningful to stroke survivors and their carers. The practical focus of the exercises,  
36  
37 411 which were tailored to stroke survivors' abilities, needs and goals and designed to enhance  
38  
39 412 the use of the affected arm in functional activities, was perceived as valuable. The  
40  
41 413 importance of a practical focus in arm rehabilitation is also highlighted by Barker and  
42  
43 414 Brauer<sup>21</sup> who found that it was important to stroke survivors to integrate the affected arm  
44  
45 415 into routine tasks.

46  
47 416 The intensity of the intervention was regarded as positive and well tolerated, and  
48  
49 417 demonstrates that at least a proportion of stroke survivors and their carers were willing to  
50  
51 418 engage in treatment that was more intensive than usual care. The amount of face-to-face  
52  
53 419 augmented treatment was low, however. The optimal dose of arm rehabilitation is much  
54  
55 420 debated.<sup>22, 23</sup> One study provided 300 hours of arm rehabilitation over 12 weeks  
56  
57 421 respectively, but these involved mostly stroke survivors in the chronic stage.<sup>23</sup> Therefore it  
58  
59 422 may not be possible to give an absolute recommendation for the treatment dose, as this  
60

1  
2  
3 423 needs to be tailored to individual tolerance and ability, and future studies should carefully  
4  
5 424 explore the acceptability of therapy dose.  
6

7  
8 425 The timing of the intervention was perceived differently in both groups. Most from the Later  
9  
10 426 group and from the Early group felt that the start of rehabilitation was acceptable to them,  
11  
12 427 which may indicate that in their individual circumstances, they felt ready to engage. This  
13  
14 428 study suggested that it may be difficult to give a recommendation for a standard time point  
15  
16 429 that is optimal - from a service user perspective - to start with augmented arm rehabilitation  
17  
18 430 after stroke.

19  
20 431 A strategy for coping with self-managed practice was to link intervention activities to  
21  
22 432 meaningful, everyday activities that stroke survivors were able to see the value of. Building  
23  
24 433 these into daily routines may help to reduce the burden of finding additional time for  
25  
26 434 treatment. A systematic review by Gallacher et al.<sup>10</sup> found that physical exercises  
27  
28 435 constituted treatment burden, but embedding exercises into a daily routine was a self-  
29  
30 436 management strategy for coping with this burden. Integrating self-management into a daily  
31  
32 437 routine is part of health behaviour change.<sup>24</sup> This may be mediated by habit formation<sup>25</sup>, i.e.  
33  
34 438 forming a new behaviour to ultimately develop automaticity.<sup>25</sup> Behaviour change requires  
35  
36 439 self-efficacy, which impacts on motivation, goal setting and how much effort is made to  
37  
38 440 achieve the goals when barriers arise<sup>26</sup> Findings from this study suggests that carers and  
39  
40 441 study physiotherapists acted as motivators and helped participants to overcome difficulties  
41  
42 442 in their rehabilitation, increasing their sense of 'mastery'.

43  
44 443 Implementing activities into a daily routine seemed to be easier for those stroke survivors  
45  
46 444 who were under the age of 70, who appeared more driven to recover or felt pressure from  
47  
48 445 social responsibilities such as parenting or employment. In particular, those stroke survivors  
49  
50 446 of working age and with families and child care duties appeared to be motivated. This  
51  
52 447 resonates with other research which has found younger stroke survivors to be motivated to  
53  
54 448 engage in rehabilitation, with their needs focusing mainly on parenting and employment.<sup>27</sup>,  
55  
56 449 <sup>28</sup> In comparison, most of the over 70 year old males in this study appeared to be less  
57  
58 450 engaged and this could be related to being less goal driven, or experiencing concurrent  
59  
60 451 mental illness. For example, Alex (EG, age 73 years) reported that he was feeling depressed.  
452  
453 Danny was in a nursing home (EG, age 84 years), which is often associated with limited life-

1  
2  
3 453 expectancy and less opportunity to engage in goal setting.<sup>6</sup> Lewis (LG, age 75 years) was  
4  
5 454 living with his wife but without children or grandchildren and seemed to have no clear focus  
6  
7 455 in his life. Only Thomas (EG, age 72 years) was determined to improve movement in his  
8  
9 456 affected arm. Given that the median age for stroke in the UK is 77 years<sup>28</sup>, this finding is  
10  
11 457 concerning.

12  
13 458 Being in control of one's rehabilitation is also a positive factor in self-management. The  
14  
15 459 mobile phone reminder helped stroke survivors to feel in control. Mclean et al.<sup>29</sup> also  
16  
17 460 reported that high motivation was related to being actively involved in rehabilitation,  
18  
19 461 whereas low motivation was associated with waiting for recovery. Most stroke survivors in  
20  
21 462 this study were self-motivated and engaged in supported self-management whilst others  
22  
23 463 who perceived more barriers to self-management were motivated by the study  
24  
25 464 physiotherapists.

26  
27 465 Results show that supportive carers and sometimes a supportive social network also  
28  
29 466 influenced the motivation to play an active role in their rehabilitation. Most stroke survivors  
30  
31 467 in this study had a carer available (Table 1) which, in their eyes, helped with their recovery  
32  
33 468 because carers acted as a reminder and sometimes assisted with the exercises. Some stroke  
34  
35 469 survivors were not receiving carer support as carers had other commitments such as work  
36  
37 470 (e.g. Ross, LG, age 63 years). In a study by Galvin et al.<sup>30</sup> on carer involvement in exercise  
38  
39 471 delivery after stroke, 91% of carers were found to be willing to help with the exercise  
40  
41 472 delivery - but this was not implemented routinely in stroke rehabilitation, as only between  
42  
43 473 21% and 36% of carers were actually involved.<sup>30</sup> The importance of involving carers was  
44  
45 474 highlighted by stroke survivors in another study by Satink et al.<sup>31</sup>, which found that stroke  
46  
47 475 survivors valued the support from carers in their self-management. However, on the other  
48  
49 476 hand family members can also inhibit stroke survivors developing self-management skills<sup>31</sup>,  
50  
51 477 which suggests that more guidance and training may be needed for carers.

52  
53 478 Finally, human contact with the study physiotherapists was seen as vital because of the  
54  
55 479 supportive nature as well as the frequency of their visits, which provided regular guidance  
56  
57 480 and support. Lehmann et al.<sup>9</sup> also found that stroke survivors engaged in intensive arm  
58  
59 481 rehabilitation with a virtual reality system valued the human interaction with the therapists  
60  
61 482 for their guidance and social interaction.

1  
2  
3 483 This study focused on stroke rehabilitation, but some of the findings may be transferable to  
4  
5 484 other long-term conditions such as head injuries, spinal cord injuries, multiple sclerosis or  
6  
7 485 Parkinson's disease, including the need for activities to have a practical focus and the  
8  
9 486 importance of a support network.

10  
11 487 This study has strengths and limitations. A qualitative approach allowed an exploration of  
12  
13 488 stroke survivors' and their carers' experiences with augmented arm rehabilitation. Most  
14  
15 489 studies on intensive arm rehabilitation to date have concentrated on outcomes. Two  
16  
17 490 feasibility studies<sup>32,33</sup> explored experiences of arm rehabilitation after stroke to some  
18  
19 491 extent, however in a very limited way as they did not use qualitative methods. A strength of  
20  
21 492 this study was that it went into much more depth about which aspects of the intervention  
22  
23 493 were acceptable, appropriate and relevant for stroke survivors and their carers, using  
24  
25 494 Normalisation Process Theory.

26  
27 495 A limitation was that this study included a selective sample; participants were probably  
28  
29 496 motivated to engage in augmented rehabilitation. However not everyone in the Early and  
30  
31 497 Later groups completed the study and for ethical considerations those who did not  
32  
33 498 complete were not involved in the interviews. Therefore, only selected findings can be  
34  
35 499 reported from this study, which may not reflect what the excluded stroke survivors and  
36  
37 500 their carers experienced. The numbers of carers interviewed was also low. However, carers  
38  
39 501 were not the unit of recruitment in this study but supplemented stroke survivors' records.  
40  
41 502 An additional limitation was that self-management activities were not logged, as no tool  
42  
43 503 could be identified that was valid and feasible for this study population across study  
44  
45 504 settings.<sup>34</sup> Therefore it is unclear how much supported self-management stroke survivors  
46  
47 505 actually engaged in. Given that the target dose of augmented arm rehabilitation was 27  
48  
49 506 additional hours, stroke survivors were expected to undertake 22 - 23 hours of supported  
50  
51 507 self-management – if they were able to. Logging the activities outside of face-face therapy  
52  
53 508 sessions would provide an objective record of the type and number of activities stroke  
54  
55 509 survivors actually undertook.

56  
57 510 The findings are relevant for clinical practice in that they show that rehabilitation, including  
58  
59 511 support for self-management after stroke, is acceptable to those who saw the relevance of  
60  
512 the rehabilitation activities for their daily lives, and were able to embed them into their daily

1  
2  
3 513 routines. The findings support the theory that supported self-management can be a positive  
4  
5 514 factor and can enhance self-efficacy in stroke rehabilitation.<sup>6</sup> Normalisation Process Theory  
6  
7 515 could be applied to routine rehabilitation practice to optimise supported self-management,  
8  
9 516 e.g. by making practitioners more aware of the alignment of self-management strategies  
10  
11 517 with people's beliefs around the meaningfulness and purpose of goals (*cognitive*  
12  
13 518 *participation and reflexive monitoring*). Normalisation Process Theory could also enable  
14  
15 519 practitioners to develop a better understanding of what is important to people, so that they  
16  
17 520 can recommend activities that are tailored to individuals and help them to find ways to  
18  
19 521 integrate these into their daily lives.

20  
21 522 More research is needed to explore the views of stroke survivors and their carers on arm  
22  
23 523 rehabilitation to understand how best to support self-management that is not only  
24  
25 524 personally meaningful and purposeful to them, but also meets their rehabilitation needs. In  
26  
27 525 a future study it would be of value to explore how well rehabilitation needs are being met in  
28  
29 526 more depth; how, under what circumstances and for whom. Findings from this study  
30  
31 527 suggest that in particular the constructs *cognitive participation* and *reflexive monitoring*  
32  
33 528 could help to answer research questions on how meeting rehabilitation needs after stroke  
34  
35 529 could be optimised.

36 530

### 39 531 **Clinical message**

- 42 532 • Stroke survivors in this study were willing to engage in augmented arm  
43 533 physiotherapy before the early sub-acute phase post stroke.
- 46 534 • Supported self-management seemed to be more acceptable to those who  
47 535 understood the relevance of the activities and incorporated them into their daily  
48 536 routines.

51  
52 537

### 55 538 **Acknowledgements**

58 539 We would like to thank all stroke survivors and their carers who participated in this study.  
59  
60 540 We express our thanks to the Chartered Society of Physiotherapy Charitable Trust for

1  
2  
3 541 funding the EVERLAP study (grant number N/12/10), and to Glasgow Caledonian University  
4  
5 542 for funding a PhD studentship for Stefanie Schnabel. We are grateful for the guidance and  
6  
7 543 support provided by our other co-applicants in the EVERLAP study: Ms. Gillian Alexander  
8  
9 544 (NHS Greater Glasgow and Clyde), Prof. Lynne Baillie (Heriot Watt University), Prof. Cam  
10  
11 545 Donaldson (Glasgow Caledonian University), Prof. Malcolm Granat (University of Salford),  
12  
13 546 Dr. Alex Pollock (Glasgow Caledonian University), Prof. Philip Rowe (Strathclyde University).  
14  
15 547 We would also like to thank Dr. Lex de Jong for conducting a number of the interviews and  
16  
17 548 Mrs. Mary Skelly for transcribing the interviews, and Prof. Maggie Lawrence for her critical  
18  
19 549 review of the manuscript.  
20  
21 550

## 22 23 551 **Appendix 1: Topic guide**

24  
25 552

## 26 27 28 553 **References**

- 29  
30 554 1. Mendis S. Stroke disability and rehabilitation of stroke: World Health Organisation perspective.  
31  
32 555 *Int J Stroke* 2013;8:3-4.
- 33  
34 556 2. Lawrence ES, Coshall C and Dundas R, et al. Estimates of the Prevalence of Acute Stroke  
35  
36 557 Impairments and Disability in a Multiethnic Population. *Stroke* 2001;32(6):1279-84.
- 37  
38 558 3. Broeks JG, Lankhorst G J, Rumping K, et al. The long-term outcome of arm function after stroke:  
39  
40 559 results of a follow-up study. *Disabil Rehabil* 1999;21(8):357-64.
- 41  
42 560 4. Morris JH, van Wijck F, Joice S, et al. Predicting health related quality of life 6 months after stroke:  
43  
44 561 the role of anxiety and arm dysfunction. *Disabil Rehabil* 2013;35(4):291-9.
- 45  
46 562 5. Pollock A, Farmer SE, Brady MC, et al. Interventions for improving arm function after stroke.  
47  
48 563 *Cochrane Database Syst Rev* 2014(11).
- 49  
50 564 6. Royal College of Physicians. National clinical guideline for stroke,  
51  
52 565 [https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-](https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx)  
53  
54 566 [Guideline-for-Stroke-5t-\(1\).aspx](https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx) (2016, accessed 17 January 2019).  
55  
56  
57  
58  
59  
60



- 1  
2  
3 567 7. Boger EJ, Demain SH and Latter SM. Stroke self-management: A focus group study to identify the  
4  
5 568 factors influencing self-management following stroke. *Int J Nurs Stud* 2015;52(1):175-87.  
6  
7 569 8. Kidd L, Lawrence M, Booth J, et al. Development and evaluation of a nurse-led, tailored stroke  
8  
9 570 self-management intervention. *BMC Health Serv Res* 2015;15:359.  
10  
11  
12 571 9. Lehmann I, Baer G and Schuster-Amft C. Experience of an arm training program with a non-  
13  
14 572 immersive virtual reality system in patients after stroke: a qualitative study. *Physiotherapy*  
15  
16 573 2020;107:317-26.  
17  
18  
19 574 10. Gallacher K, Morrison D, Jani B, et al. Uncovering treatment burden as a key concept for stroke  
20  
21 575 care: a systematic review of qualitative research. *PLoS Med* 2013;10(6).  
22  
23 576 11. Gallacher KI, May CR, Langhorne, P, et al. A conceptual model of treatment burden and patient  
24  
25 577 capacity in stroke. *BMC Fam Pract* 2018;19(9).  
26  
27  
28 578 12. May C, Rapley T, Mair FS, et al. Normalization Process Theory On-line Users' Manual, Toolkit and  
29  
30 579 NoMAD instrument, <http://www.normalizationprocess.org> (2015, accessed 24 January 2019).  
31  
32 580 13. Department of Health & NHS. Creating a Patient-led NHS - Delivering the NHS Improvement Plan,  
33  
34 581 [https://webarchive.nationalarchives.gov.uk/20130104225658/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4106506](https://webarchive.nationalarchives.gov.uk/20130104225658/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4106506) (2005, accessed 14  
35  
36 582 February 2019).  
37  
38  
39 583  
40  
41 584 14. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ):  
42  
43 585 a 32-item checklist for interviews and focus groups. *Int J Qual Health C* 2007;19(6):349-357.  
44  
45 586 15. Van Wijck, F. EVERLAP: Early VERsus Later Augmented Physiotherapy compared with usual arm  
46  
47 587 rehabilitation: an exploratory RCT of arm function after stroke. Study protocol,  
48  
49 588 <http://www.isrctn.com/ISRCTN32522341?q=&filters=&sort=&offset=2&totalResults=17312&page=1&pageSize=10&searchType=basic-search> (2014, accessed 14 December 2018).  
50  
51 589  
52  
53 590 16. Morris SM. Joint and Individual Interviewing in the Context of Cancer. *Qual Health Res*  
54  
55 591 2001;11:553-567.  
56  
57  
58  
59  
60



- 1  
2  
3 592 17. Wilson AD, Onwuegbuzie AJ and Manning LP. Using Paired Depth Interviews to Collect Qualitative  
4  
5 593 Data. *Qual Rep* 2016;21:1549-73.  
6  
7 594 18. Murray E, Treweek S, Pope C, et al. Normalisation process theory: a framework for developing,  
8  
9 595 evaluating and implementing complex interventions. *BMC Med* 2010; 8:63.  
10  
11  
12 596 19. Mulhall A. In the field: notes on observation in qualitative research. *J Adv Nurs* 2003;41:306-13.  
13  
14 597 20. Spencer L, Ritchie J, O'Connor W, et al. Analysis in practice. In: Ritchie J, Lewis J, McNaughton  
15  
16 598 Nicholls C, et al. (eds) *Qualitative research practice: a guide for social science students and*  
17  
18 599 *researchers*. 2nd ed. London: Sage; 2014, pp.296-345.  
20  
21 600 21. Barker RN and Brauer SG. Upper limb recovery after stroke: The stroke survivors' perspective.  
22  
23 601 *Disabil Rehabil* 2005;27:1213-23.  
24  
25 602 22. French B, Thomas LH, Coupe J, et al. Repetitive task training for improving functional ability after  
26  
27 603 stroke (Review). *Cochrane Database Syst Rev* 2016(11).  
28  
29 604 23. McCabe J, Monkiewicz M, Holcomb J, et al. Comparison of Robotics, Functional Electrical  
30  
31 605 Stimulation, and Motor Learning Methods for Treatment of Persistent Upper Extremity  
32  
33 606 Dysfunction After Stroke: A Randomized Controlled Trial. *Arch Phys Med Rehabil* 2015;96:981-90.  
34  
35 607 24. Dobkin BH. Behavioral self-management strategies for practice and exercise should be included in  
36  
37 608 neurologic rehabilitation trials and care. *Curr Opin Neurol*. 2016;29:693-9.  
38  
39 609 25. Lally P and Gardner B. Promoting habit formation. *Health Psychol Rev* 2013;7:S137-58.  
40  
41 610 26. Bandura A. Self-efficacy: Toward a Unifying Theory of Behavioral Change. *Psychol Rev*  
42  
43 611 1977;84:191-215.  
44  
45 612 27. Lawrence M and Kinn S. Needs, priorities, and desired rehabilitation outcomes of family members  
46  
47 613 of young adults who have had a stroke: findings from a phenomenological study. *Disabil Rehabil*  
48  
49 614 2013;35:586-95.  
50  
51 615 28. National Institute for Health and Care Excellence. Stroke and transient ischaemic attack in over  
52  
53 616 16s: diagnosis and initial management,  
54  
55 617 <https://www.nice.org.uk/guidance/ng128/chapter/Context#:~:text=The%20average%20age%20of%20stroke,hospitalised%20per%20year%20in%20England> (2019, accessed 03 August 2020).  
56  
57  
58  
59  
60

- 1  
2  
3 619 29. Maclean N, Pound P, Wolfe C, et al. Qualitative analysis of stroke patients' motivation for  
4 rehabilitation. *BMJ* 2000;32:1051-4.  
5 620  
6 621 30. Galvin R, Cusack T and Stokes E. To what extent are family members and friends involved in  
7  
8 622 physiotherapy and the delivery of exercises to people with stroke? *Disabil Rehabil* 2009;31:898-  
9 623 905.  
10  
11 624 31. Satink T, Cup EHC, de Swart BJM, et al. How is self-management perceived by community living  
12  
13 625 people after a stroke? A focus group study. *Disabil Rehabil* 2015 02;37:223-30.  
14  
15 626 32. Brkic L, Shaw L, van Wijck F, et al. Repetitive arm functional tasks after stroke (RAFTAS): a pilot  
16  
17 627 randomised controlled trial. *Pilot Feasibility Stud* 2016;2(50).  
18  
19 628 33. Turton AJ, Cunningham P, van Wijck F, et al. Home-based Reach-to-Grasp training for people  
20  
21 629 after stroke is feasible: A pilot randomised controlled trial. *Clin Rehabil* 2016;14:1-13.  
22  
23 630 34. Frost R, Levati S, McClurg D, et al. What Adherence Measures Should Be Used in Trials of Home-  
24  
25 631 Based Rehabilitation Interventions? A Systematic Review of the Validity, Reliability, and  
26  
27 632 Acceptability of Measures. *Arch Phys Med Rehabil* 2017;98:1241-56.e45.  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

**Table 1: Characteristics of study participants**

Characteristics Stroke survivors (pseudonyms)	Sex	Age (years)	Marital status	Occupational status at the time of the interview	Carer available	Consenting carer interviewed	Group allocation	Type of stroke	NIHSS	ARAT
Maureen	F	72	Married	Retired	Yes	No	LG	Haemorrhagic	2	25
Brigit	F	65	Single	Retired	No	No	EG	Ischaemic	13	57
Ross	M	63	Married	Retired	Yes	No	LG	Ischaemic	5	27
Simon	M	65	Single	Retired	Yes	Yes	LG	Haemorrhagic	13	0
Anthony	M	56	Married	Working	Yes	Yes	LG	Ischaemic	5	3
Timo	M	49	Married	Off sick	Yes	Yes	LG	Haemorrhagic	9	0
Lewis	M	75	Married	Retired	Yes	No	LG	Ischaemic	10	3
Jackie	F	82	Married	Retired	Yes	No	EG	Ischaemic	13	0
Chris	M	56	Single	Unemployed	No	No	LG	Ischaemic	1	55
Lydia	F	40	Married	Off sick	Yes	No	EG	Ischaemic	8	0
Sean	M	68	Has partner	Working	Yes	Yes	LG	Ischaemic	4	51
Alex	M	73	Has partner	Retired	Yes	No	EG	Ischaemic	0	48
Peter	M	64	Married	Retired	Yes	No	LG	Ischaemic	3	54
Janet	F	74	Single	Retired	Yes	Yes	EG	Ischaemic	3	14
Thomas	M	72	Has partner	Retired	No	No	LG	Ischaemic	10	0
Danny	M	84	Widower	Retired	No	No	EG	Ischaemic	12	3
Lyn	F	76	Married	Retired	Yes	No	EG	Ischaemic	6	0

1  
2  
3 Table (1): Overview of demographics and baseline clinical characteristics of the stroke survivors included in interviews (names are false); F = Female; M = Male; EG = Early  
4 group; LG = Later group; ARAT = Action Research Arm Test which measures upper limb performance, scores range from 0 – 57 and a maximum of 57 indicating normal  
5 performance; NIHSS = National Institute for Health Stroke Scale which evaluates the neurological status after stroke, scores range from 0 – 42, with the score 0 indicating  
6 no abnormal neurological status after stroke  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46

For Peer Review

**Table 2: Mapping the findings according to the main constructs of Normalisation Process Theory**

	<b>Coherence</b>	<b>Cognitive participation</b>	<b>Collective action</b>	<b>Reflexive monitoring</b>
<b>Acceptability of the intervention</b>	Subtheme 1.1: Experiences with the intervention	Subtheme 1.1: Experiences with the intervention	Subtheme 1.2: Experiences with the therapist-led sessions	Subtheme 1.3: Intensity and timing of the intervention  Subtheme 1.4: Relevance of the intervention
<b>Supported self-management</b>	Subtheme 2.2: Motivation for supported self-management	Subtheme 2.1: Engagement in supported self-management	Subtheme 2.4: Barriers and facilitators to engaging in supported self-management	Subtheme 2.3: Appropriateness of supported self-management
<b>Coping with the intervention</b>	Subtheme 3.2: Being actively involved	Subtheme 3.1: Importance of a support network	N/D	N/D

Table (2): mapping the findings according to the main constructs of Normalisation Process Theory; Themes = Acceptability of the intervention, Supported self-management, Coping with the intervention; N/D = no data

## Appendix 1: Topic guide

### Topic guide

#### Start recording the interview

The interview will cover a range of aspects of both the intervention and the assessment procedures related to augmented upper limb physiotherapy:

1. What has life been like after the stroke?
2. How do you adapt to the changes?

#### Prompts:

- Support from others (family, carer, NHS community team)
  - Changes in daily routine
  - Change in leisure time activities
3. What was your experience with the upper limb physiotherapy?
    - In usual care (physiotherapy received in hospital or community NHS)
    - On the EVERLAP study
  4. How relevant / not relevant did you find the exercises to your arm impairment?
    - In usual care
    - On the EVERLAP study
  5. How did you find the timing of the programme (3 weeks / 9 weeks post stroke) and the duration (over 6 weeks)?
  6. How did you find the dose of the upper limb physiotherapy (45 mins/day)?
    - How did you cope with the amount of exercises?
  7. Can you recall ways (strategies) that helped you to manage the amount of exercises?

**Prompts:**

- Help from others (family members, carers, health professionals)
- Motivation
- Goal setting
- Implementation in daily routine

8. Can you tell me a bit about how you got on in the therapist-led sessions and the self-practice?

- From which of the two sessions (therapist-led and self-practice) did you benefit the most?
- How appropriate was the guidance from the research physiotherapists during the therapy-led session?
- How appropriate was the self-practice at that stage of the rehabilitation process?
- Were there any barriers to self-practice?

**Prompts:**

- Tiredness
- Pain
- Other health conditions
- Other commitments
- Not enough support

9. How did you find the reminders (DVD or mobile phone or workbook) for the self-practice?

10. How did you find the assessments e.g. the use of an accelerometer and video?

11. How did you experience your role as a carer in the augmented upper limb physiotherapy?

- Which tasks were attached to your role as carer in the intervention?

12. What kind of guidance did you as a carer receive from the research physiotherapists?

1  
2  
3  
4  
5 13. What impact did the intervention have on your and your partner's quality of life?  
6

7 **Prompts:**

- 8 - Mood  
9  
10 - Energy level  
11  
12 - Independence in daily living  
13  
14 - Social life  
15  
16 - Work  
17  
18

19  
20 14. Do you have any suggestions for improvements of the assessments or the  
21 intervention?  
22

23  
24  
25 15. Is there anything else you want to mention that has not been covered by this  
26 interview and which you think is important for us to take on board?  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60