



University of Dundee

Physical activity participation in community dwelling stroke survivors

Morris, Jacqui H.; Oliver, Tracey; Kroll, Thilo; Joice, Sara; Williams, Brian

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1 Introduction

2 Stroke is a global health problem. Annually 16 million stroke events occur worldwide
3 and 62 million stroke survivors live with stroke consequences [1]. Stroke causes
4 motor and functional impairment, restricting participation in social and leisure
5 activities, negatively influencing survivors' quality of life [2]. Risk of stroke
6 recurrence is high, at 26% five years post-stroke [1].

7

8 Regular participation in physical activity (PA) can ameliorate recurrence, improve
9 functional mobility, walking capacity [3], muscle strength [3], bone density [4] and
10 quality of life [5]. Stroke guidelines recommend survivors undertake three aerobic,
11 flexibility and strengthening exercise sessions per week for health benefits [6]. In
12 response, post-rehabilitation exercise services have been developed, often led by
13 physiotherapists. Despite such developments, around 70% of survivors undertake
14 minimal post-rehabilitation PA [7], causing low fitness levels compared to age-
15 matched peers. This deconditioning compounds stroke effects, worsening physical
16 disability [6]. Understanding beliefs, attitudes, barriers and facilitators to PA
17 behaviour is therefore vital.

18

19 Previous qualitative studies and surveys highlight *pragmatic* and clinical barriers and
20 facilitators to PA, including physical effects of stroke, social and instrumental
21 support, transport availability, and costs [8-10], however beliefs and attitudes, which
22 are important determinants of PA, have not been fully explored after stroke [10] .

23 Existing evaluations of barriers to PA were conducted mainly with African American
24 populations [11], with survivors within other studies [12], members of existing stroke

25 groups [12] or conveniently selected ambulatory survivors [13-15]. These studies
26 may not present sufficiently diverse perspectives to fully understand the challenges
27 faced by survivors. Views of survivors purposefully selected to have diverse
28 disabilities, age ranges and socio-demographic status should thus be elicited.

29

30 Physiotherapists frequently play a role in PA promotion after stroke. Our previous
31 qualitative study shows that physiotherapists often see survivors' PA motivation as
32 un-modifiable and report little expertise in addressing survivors' motivation and
33 health behaviours [16]. Those views seem to influence how physiotherapists'
34 promote PA with survivors; particularly their efforts to support survivors whom they
35 believe have low motivation. Therefore, if physiotherapists are to successfully
36 support stroke survivors to be active, they require the skills to fully understand and
37 explore issues survivors face to participation in PA.

38

39 This study explored attitudes, beliefs, barriers and facilitators to PA of a purposefully
40 selected sample of survivors, to seek to understand influences on PA participation.

41 Specific research questions were:

- 42 • What are stroke survivors' beliefs about the role and importance of PA in
43 stroke recovery?
- 44 • What are survivors' experiences, beliefs and attitudes towards PA after
45 rehabilitation and what meanings do they ascribe to PA?
- 46 • What barriers and facilitators to participation in PA do survivors experience?
47 How do these influence decisions to engage in PA?

48

49 We also aimed to develop an explanatory model to enhance understanding of PA
50 after stroke and to guide development of tailored, acceptable PA interventions
51 within physiotherapists' scope of practice.

52

53 **Methods**

54 A qualitative design was used to explore stroke survivors' beliefs, experiences and
55 barriers to PA [17, 18]. In-depth interviews allowed interviewees' responses to be
56 probed and clarified, providing data grounded in interviewees' lives. We also
57 conducted focus groups with carers and physiotherapists. Comparison between
58 physiotherapists' and survivors' views is reported elsewhere [16].

59

60 East of Scotland Research Ethics Service granted ethical approval (reference
61 10/S1401/47).

62

63 **Sampling and Recruitment**

64 Community dwelling stroke survivors were eligible for participation six months after
65 discharge from rehabilitation, if able to provide informed consent. We sampled by
66 gender, age, physical disability and deprivation to capture views from survivors for
67 whom these factors may have influenced PA participation [19].

68

69 Community stroke liaison nurses from two Scottish health boards sent invitation
70 letters to 260 potential participants. The study researcher contacted ninety
71 respondents by telephone for screening, and preliminary match to sampling criteria.

72 The researcher (TO) was a female health psychologist experienced in qualitative

73 research in healthcare settings . Full screening for those matching sampling criteria
74 was conducted at participants' homes before interview. Screening tools for sampling
75 criteria [20-24] are described in Supplementary Information, Table A. Previous work
76 [25] suggested we would reach the point at which no new ideas emerge with 30-40
77 participants; therefore target recruitment was 36 participants.

78

79 **Data Collection**

80 Face-to-face semi-structured interviews of one hour were conducted by TO at
81 participants' homes, with 38 survivors. Two participants were interviewed using
82 Talking Mats Framework [TMF]^{®*}, a communication tool adapted to match topic
83 guides [26]. Interviews were audio recorded and TMF[®] interviews were video-
84 recorded. All were fully transcribed.

85

86 **Topic guide**

87 The topic guide (see Supplementary Information, Table B) drew on psychological
88 concepts known to influence health behaviours. Leventhal's Common-Sense Model
89 of Illness Representation (CSM) suggests beliefs about cause and consequences of
90 illness inform how individuals develop coping strategies and action plans to deal with
91 their illness, and how they appraise expected outcomes [27]. We examined these
92 concepts in relation to stroke and physical activity. We also drew on the concept of
93 self-efficacy within Bandura's Social Cognitive Theory, concerned with confidence to
94 achieve expected outcomes [28]. Self-efficacy is known to influence uptake and
95 maintenance of PA [6]. Although drawing on the concepts, we were not limited by
96 them, and also examined barriers and facilitators more generally, aiming to maintain

97 an essentially inductive approach. Emerging issues were included in subsequent
98 interviews, maintaining an inductive approach. Documented field-notes also
99 informed data interpretation.

100

101 **Data Analysis**

102 Framework Approach [29, 30] guided data analysis and NViVO 9 software facilitated
103 data organization. Framework was selected because it is particularly useful for
104 conducting applied qualitative research and for analysis by teams of researchers.
105 TO read and coded transcripts according to a) initial research questions b)
106 explanatory theoretical concepts described above. She was also alert to emergent
107 issues. Two additional researchers [JM, TK] applied coding to nine transcripts each,
108 providing inter-coder verification and establishing agreement about the coding
109 framework. We opted to review the eighteen transcripts to ensure participants
110 across the sampling framework were represented, and that half the transcripts were
111 reviewed by two researchers. Researchers next aggregated codes into higher order
112 themes informed by research questions, apriori theoretical concepts and emerging
113 issues. The thematic framework was applied to all transcripts by TO. Themes were
114 agreed and added as they emerged from subsequent interviews until all transcripts
115 were indexed. Data were summarised and inserted into thematic charts organised by
116 case, major themes and sub-themes[29] . The final thematic framework was refined
117 by agreement between all researchers [JM, TO, TK, SJ, BW]. Constant comparison
118 across themes and between cases ensured systematic data comparison for mapping
119 and refinement of higher order concepts[29]. New relationships between concepts
120 were sought until our final conceptual model was defined. Where disagreements

121 occurred, researchers clarified concepts and searched transcripts to inform accurate
122 text interpretation. Analytical themes are presented in Supplementary Information,
123 Table C, and in a final conceptual model Figure 1. A final group session with stroke
124 survivors [n=5] and carers (n=4) established credibility, accuracy and completeness
125 of our interpretation [18].

126

127 **Results**

128

129 **Participant Characteristics**

130 We recruited 19 male and 19 female participants aged between 23 and 85 years, and
131 8 months to 30 years post-stroke (Table 1). Twenty-one participants were
132 categorised by Carstairs Index as having high socioeconomic status, and Barthel
133 Index scores ranged from 60 to 100, denoting diverse physical disabilities.

134

135 **Findings**

136 Barriers and facilitators coalesced around motivation (defined as ‘desire to be
137 active’) and capabilities (defined here as ‘resources to be active’). These concepts
138 emerged from survivors’ attitudes and experiences of PA, and their physical, social
139 and environmental context. Survivors appeared to experience motivation and
140 capability as synergistic or dissonant, and interaction between motivation and
141 capability seemed to determine survivors’ PA participation. Dissonance occurred
142 when motivated survivors had limited capability for PA, causing frustration, or, when
143 survivors had capability but little desire for activity. Confidence to achieve goals and
144 determination to overcome barriers acted as activity catalysts when other influences

145 were synergistic. Below, we explain concepts before illustrating in an explanatory
146 model their influence on PA participation.

147

148 **Influences on Physical Activity Motivation**

149

150 **Beliefs, experiences and attitudes to PA and stroke recovery**

151

152 Beliefs and attitudes ascribed to PA reflected its value relative to stroke recovery,
153 which in turn influenced motivation.

154

155 *PA as incidental to recovery*

156 Many survivors viewed stroke recovery as a natural process over which they had
157 little control (Table 2, quote a). Some survivors, often older, only participated in PA
158 that was integrated and incidental to everyday living. Intentionally engaging in PA to
159 enhance recovery was uncommon, and activity was associated with “getting by” in
160 everyday life (Table 2, Quote b). Attitudes stemmed from the mental and physical
161 effort of PA that was additional to already difficult lives (Table 2, Quote c).

162

163 *Insert Table 2 about here*

164

165 *PA as central to recovery*

166 Other survivors prioritised PA as structured, planned exercise. They were often
167 younger, motivated to participate in organised exercise, with clear expectations of
168 physical benefits, despite disability (Table 2, Quote d). They attributed stroke to

169 medical conditions or lifestyle behaviours that could be ameliorated by PA.

170 Consequently, PA appeared important for recovery and future prevention, and

171 benefits were relevant to post-stroke life.

172

173 *PA as a social facilitator*

174 Some survivors, often younger, expressed social and occupational drivers for

175 recovery, including family, work, and social roles, representing desire for fulfilling

176 lives. PA was thus prioritised for its potential to facilitate participation in wider life

177 roles despite effort involved (Table 2, Quote e). Other survivors expressed more

178 direct social benefits of PA. These survivors enjoyed PA, viewing it as pleasurable

179 activity and were motivated by return to the social sense of self that it offered (Table

180 2, Quote f) or because it passed time (Table 2, Quote g).

181

182 *Role of pre-stroke PA behaviour*

183 These beliefs were frequent if survivors had undertaken pre-stroke PA, saw it as part

184 of their identity and *expected* physical benefits of PA to influence recovery, (Table 2,

185 Quote h). However, attempts to return to pre-stroke activities were sometimes

186 undermined by frustration resulting from lost skills. Failure to achieve expected

187 benefits sometimes led to loss of enthusiasm (Table 2, Quote i). Conversely,

188 survivors who had never been active did not see PA as part of their identity, making

189 purposeful engagement unlikely (Table 2, Quote j).

190

191 In summary, beliefs about stroke cause, recovery, enjoyment and expectations of

192 benefits influenced desire, or motivation to participate, beyond daily tasks.

193 Although physical disability influenced actual activity, many survivors were
194 motivated, irrespective of disability, if other drivers were strong.

195

196 **Perception of Capability for Physical Activity**

197 Translation of motivation into actual activity appeared dependent on perceptions of
198 capability for PA. Capability stemmed from appraisal of internal and external
199 influences representing barriers or facilitators to activity. *Intrinsic influences* included
200 physical effects, emotional and cognitive responses to stroke, and confidence in an
201 individual's ability to engage in any specific activity. *Extrinsic influences* included
202 support from others, and environmental barriers or facilitators. These influences are
203 described below with exemplary quotes in Table 3.

204

205 Insert Table 3

206

207 **Intrinsic Influences on capability**

208

209 ***Direct effects of stroke***

210 Physical effects of stroke, including weakness and balance problems, influenced
211 perceived capability, presenting barriers to activity. Several survivors also reported
212 that communication difficulties reduced their confidence to attend organised
213 classes. Physical effects of stroke were often compounded by co-morbidities or
214 fatigue, which limited capability, preventing even motivated survivors from being
215 active (Table 3, quote a).

216

217 ***Cognitive and emotional effects of stroke***

218 *Mood*

219 The influence of mood on survivors' PA stemmed sometimes from post-stroke
220 depression and in some cases from previous mental health problems. Many
221 survivors experienced low post-stroke mood, or depression, negatively influencing
222 perceived capability for PA. This was sometimes related to perceptions of physical
223 and social impacts of stroke, (Table 3, quote b). In contrast, some survivors with pre-
224 existing mental health problems prioritised PA to maintain and improve mood, as
225 they had done pre-stroke, and they saw achieving and maintaining capability for PA
226 as vital to their wellbeing.

227

228 *Fear*

229 Fear of negative consequences of PA also influenced perceived capability for PA and
230 could prevent survivors from translating motivation into action. Fear often stemmed
231 from perceptions of poor balance and possibility of falling (Table 3, quote 5c). For
232 others, fear of another stroke caused by PA was weighed against concern of
233 inactivity causing another stroke. This led to careful consideration before committing
234 to PA. Development of coping strategies around fear was important (Table 3, quote
235 5d).

236

237 *Embarrassment*

238 Embarrassment stemmed from survivors' self-consciousness about exercising in
239 public places and how others might perceive them. The gym environment, with
240 mirrors and emphasis on conforming to images of physical perfection exacerbated

241 embarrassment and many survivors were uncomfortable exercising or even going
242 there (Table 3, quote e).

243

244 ***Psychological influences***

245

246 *Confidence*

247 Confidence commonly influenced PA participation. Where survivors felt confident to
248 try activities, physical disabilities presented doubts about success, generating
249 caution. Where attempts at activity were unsuccessful, confidence was lowered,
250 perceived capability for PA undermined, and motivation was lost. In this way,
251 capability and motivation were linked (Table 3, quote 5f). Conversely, survivors
252 became confident by mastering difficult activities. Success translated to confidence
253 in general capability to be active, enhancing motivation (Table 3, quote g).

254

255 *Determination*

256 Determination to overcome stroke and recover sense of self was linked to
257 confidence. This expression of willpower enhanced perceived capability and
258 motivated some survivors, even those with severe disability, to engage in activity to
259 overcome stroke. In turn, confidence or self-efficacy improved and motivation to
260 continue was enhanced. Younger survivors with family commitments commonly
261 expressed determination, but older survivors also demonstrated determination for
262 recovery (Table 3, quote h). Some older survivors simply accepted their situation
263 however (Table 3, quote i). Their capability *and* motivation were affected by co-
264 existence of age, co-morbidity, disability and limited interest in PA.

265

266 **Extrinsic influences on capability**

267 ***Social Support***

268 *Role of Health Professionals*

269 Participants viewed health professionals, particularly physiotherapists as facilitators
270 of PA. However therapy could be facilitatory or frustrating. It was time-limited, and
271 self-management advice was not always provided. Frustration was common when
272 physiotherapists did not tailor self-directed exercises to survivors' disabilities (Table
273 3, Quote j). Conversely, effective self-management support for PA enhanced
274 survivors' capability and confidence (Table 3, quote k).

275

276 *Role of family members*

277 Family often provided instrumental support to enable motivated survivors to be
278 active. However survivors valued this support in different ways. Over-protective
279 family appeared to undermine survivors' autonomy, which sometimes led to
280 resentment (Table 3, quote l). Some family members were directive, which whilst
281 resented by some, spurred others to activity because it reflected normal interactions
282 within relationships (Table 3, quote m). Survivors valued caring approaches that
283 supported their autonomy to be active in ways they desired (Table 3, quote n).

284

285 *Role of other survivors*

286 Opportunities for PA with other survivors were valued and enhanced perceived
287 capability to be active. Other survivors provided moral support and were viewed as
288 role models for what could be achieved. Seeing others recover, provided survivors

289 with a frame of reference for their own recovery potential (Table 3, quote o).
290 However, some survivors, typically male, preferred to exercise alone, reporting this
291 as their lifelong preference (Table 3, quote p).

292

293 ***Environmental Influences***

294 Environmental barriers to PA stemmed from transport availability and accessibility
295 (Table 3, quote q), lack of knowledge of opportunities, high costs of organised
296 activity, inclement weather and inconvenient timing of opportunities (Table 3, quote
297 r). These were pragmatic barriers to capability influencing whether participants
298 shifted from motivation to activity.

299

300 **Synergy and Dissonance between Motivation and Capability**

301

302 Many survivors overcame pragmatic barriers to PA through adjusted expectations of
303 what was possible (Table 3, quote s). However, where performance of previously
304 valued activities was perceived unsatisfactory, dissonance between motivation and
305 capability for PA could cause *frustration* (Table 3, quote t). In response, some
306 survivors selected more achievable activities; others expressed determination to
307 overcome barriers (Table 3, quote u); whereas those with fewer concrete beliefs
308 about PA and recovery, just accepted limitations and frustration as part of post-
309 stroke life (Table 3, quote v). In contrast, where capability and motivation were
310 synergistic and barriers could be overcome, survivors chose to be active despite
311 physical and other challenges (Table 3, quote w).

312

313

314 **Discussion**

315 Synergy and dissonance between motivation and capability appear critical to
316 understanding stroke survivors' attitudes to PA, as we illustrate in our explanatory
317 model (Figure 1). Our model (Figure 1) illustrates the dynamic nature of these
318 interactions and provides a framework to inform physiotherapists' understanding of
319 PA participation that will guide development of person-centred approaches
320 facilitating survivors' PA.

321

322 Although motivation and capability have been previously identified as influencing
323 post-stroke PA [15, 31] we believe our model provides a more nuanced explanation
324 of interactions between pragmatic and conceptual issues faced by survivors.
325 Findings suggest addressing survivors' beliefs about PA, by providing information
326 about its role in stroke recovery, coupled with motivational, behavioural and
327 pragmatic support to address capability, will enable physiotherapists to better
328 facilitate survivors' PA participation. The findings endorse recommendations that
329 skills to understand and support behaviour change should be within
330 physiotherapists' toolkit [32].

331

332 As predicted by Leventhal's model [27], which in part informed our topic guide,
333 survivors with few coherent beliefs about stroke cause, prevention and recovery
334 appeared least likely to prioritise PA, and least motivated to address barriers
335 influencing their capability for PA. This passive synergy between motivation and
336 capability meant they were unlikely to use PA as a coping strategy for recovery.

337 Others, whose stroke beliefs supported PA, created synergies between motivation
338 and capability leading to PA participation, often despite limiting disabilities. Findings
339 illustrate complex influences on survivors' motivation and illustrate why
340 physiotherapists must understand how survivors' beliefs influence their behaviour.

341

342 Data also illustrated how confidence to overcome *pragmatic, environmental* barriers
343 to PA, such as transport and negotiating leisure centres, appeared to influence
344 perceived capability. Confidence to address barriers in turn enhanced *motivation* for
345 activity, illustrating the synergistic relationships between motivation and capability.

346 As we predicted, the finding aligns with Bandura's social cognitive theory [28], which
347 proposes self-efficacy, or confidence to *successfully* undertake activities, determines
348 motivation *and* translation of motivation into behaviour. Physiotherapists are
349 important facilitators of PA after stroke [16, 33]. Our data suggests exploring
350 survivors' self-efficacy for PA and finding activities survivors can successfully
351 undertake despite disabilities, will enhance physiotherapists' facilitation of
352 behaviour change.

353

354 Although not anticipated a priori, self-determination was an emergent theme within
355 our analysis. Survivors with high determination reported being motivated to
356 overcome diverse barriers to PA capability, leading to synergy between motivation
357 and capability that facilitated activity. The finding aligns with Deci's self-
358 determination theory [34] in proposing that autonomous determination for outcome
359 achievement predicts sustained activity. Self-determination theory has been shown
360 in a systematic review of motivational interviewing in physiotherapy to be a

361 successful way to improve adherence to physiotherapy-led PA in other conditions
362 [32]. Our findings endorse the importance to physiotherapists of understanding the
363 role played by self-determination in PA after stroke, and suggest this theory should
364 also inform physiotherapists' assessment of survivors' attitudes and beliefs about
365 PA, and the development of new tailored interventions to support survivors' PA.

366

367 Frustration occurred when survivors reported dissonance between high motivation
368 and low capability. The finding aligns with another qualitative study involving five
369 young stroke survivors, in suggesting frustration emerges from tension between
370 desire for recovery and limitations imposed by stroke-related impairment [35]. For
371 physiotherapists, ascertaining outcomes survivors want to achieve from PA, and
372 addressing barriers to achievable goals may foster determination and generate
373 synergy between motivation and capability. This may require physiotherapists to be
374 creative in seeking activities that enable participation despite limited physical
375 capability.

376

377 Age seemed to influence determination, with older survivors citing effort and old age
378 as accepted limitations to capability. Such acceptance of age-related limitations may
379 reflect adjustment to declining capabilities as life progresses [36, 37]. The challenge
380 to physiotherapists is to promote PA by seeking to understand older survivors'
381 motivation and tailoring strategies to address attitudes and barriers faced by older
382 survivors.

383

384 Reflecting other qualitative studies, cost, transport, opportunities, and inclement
385 weather were external barriers to capability [12, 38]. Congruently, systems wide
386 approaches, drawing on socio-ecological models, linking health, social care, sport
387 and leisure services, and design of accessible environments are necessary to provide
388 accessible options for survivors irrespective of age, demographic status, weather and
389 personal preferences [10, 33, 39]. Physiotherapists are key players in facilitating
390 development of systems-wide approaches through their links between health, social
391 care, leisure and public health [33]. Our model paves the way for physiotherapists to
392 contribute to these larger systems by providing a dynamic, fine-grained evaluation of
393 PA barriers faced by survivors.

394

395 Physiotherapists are key professionals for PA promotion after stroke. They therefore
396 have responsibility to understand multi-layered barriers to physical activity facing
397 survivors and how motivation and capability interact to influence survivors' PA.

398 Applying the model to PA promotion after stroke, will better equip physiotherapists
399 to understand why survivors choose to be active or not.

400

401 **Implications for research, practice and policy**

402 Future research should develop and test tools to assess interactions between
403 motivation and capability to support physiotherapists to facilitate survivors' uptake
404 of PA as part of stroke recovery following rehabilitation. Our model provides unique
405 information for development of a new assessment tool. The tool will enable
406 physiotherapists to explore PA barriers with their patients in in-depth ways that
407 physiotherapists have not previously had the skills to do. The tool will be linked to a

408 shared decision-making algorithm to guide therapists and survivors towards,
409 evidence-based solutions to PA participation, individualised to survivors' situation
410 and context. Assessing and addressing survivors' motivation and capability thus will
411 enhance physiotherapists' skills in behaviour change and facilitate development of
412 new strategies to translate PA intentions into actions. Developing and testing new
413 stroke specific behavioural interventions to integrate our model with existing
414 behaviour change interventions, and within appropriate socio-ecological frameworks
415 requires future research. Collaborative approaches with survivors, their families and
416 physiotherapists to ensure fit with current practice and diverse health and social
417 care contexts are required. Furthermore, policy makers must provide accessible
418 environments, transport and appropriate facilities to address pragmatic barriers to
419 activity faced by survivors.

420

421 **Limitations and Strengths**

422 We sought diverse survivor views through purposive sampling; however nurses may
423 have introduced recruitment bias by selecting survivors they considered most
424 appropriate. Our structured topic guides sought to elicit comprehensive data
425 however, participant accounts may have been reframed by retrospective bias.
426 Nonetheless, this study enhances previous PA barriers research by providing a
427 conceptual and pragmatic framework for physiotherapists' facilitation of PA.

428

429 **Conclusion**

430 Promoting PA after stroke requires evaluation of nuanced synergies between
431 motivation and capability and a conceptual and pragmatic shift towards

432 interventions that achieve synergy between these concepts. Our model will support
433 physiotherapists' assessment of barriers and facilitators to PA and inform
434 development of person-centred interventions to promote survivors' sustained
435 participation in PA for health and recovery after stroke.

436

437 **Declarations**

438

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441

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443

444

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