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1 **Title**

2

3 The effect of a dysfunctional upper-limb on community dwelling stroke-

4 survivors and their carers: An interpretative phenomenological analysis.

5

6

7

8 **Abstract**

9

10 **Objectives:**

11 The post-stroke upper-limb continues to pose a myriad of physical and
12 psychological challenges for patients and caregivers. To optimise existing
13 services, this study firstly aimed to explore the experiences of both stroke
14 survivors and caregivers, and secondly identify their ongoing needs.

15

16 **Methods:**

17 A qualitative approach was utilised for this study. Six participants (3 stroke
18 survivors and 3 caregivers) were purposively sampled from community stroke
19 groups. Semi structured interviews were utilised to collect experiential data,
20 which were analysed using an interpretative phenomenological approach.

21

22 **Results:**

23 Three master themes emerged from data analysis: 'Finding a way forwards
24 from a poor start', 'The battle with the upper-limb' and 'Relationships with self
25 and society'. All participants, seemingly affected by disappointing services,
26 expressed negative views of rehabilitation. Misplaced or persistent hope,
27 losses in control and reduced autonomy may have contributed to poor
28 functional outcomes and perceptions of rehabilitation services. The complex

1 physical and psychological impact of the experience of the dysfunctional
2 upper-limb was also associated with ongoing and unmet support needs for
3 stroke survivors and carers.

4
5

6 **Conclusions:**

7 Healthcare professionals may consider the varying impact of the dysfunctional
8 upper-limb during decision-making and treatment planning, particularly during
9 acute rehabilitation. Future research could explore therapists' perceptions and
10 experiences of upper-limb rehabilitation during this period.

11

12 **Keywords:** Stroke, Qualitative, Rehabilitation, Dysfunctional upper-limb

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1 **Introduction**

2 Stroke is estimated to be the largest cause of adult disability in England
3 (National Audit Office, 2010). The majority of stroke survivors experience
4 persistent upper-limb impairments, with only half regaining functional use after
5 six months (Kwakkel et al., 2003). Ongoing physical and psychological
6 sequelae include detrimental effects on activities of daily living (ADL's),
7 independence (Faria-Fortini et al., 2011), changes in role and impaired
8 wellbeing (Wiles et al., 2002). This physical and psychological impact is
9 evident in research demonstrating stroke survivors' unmet needs and reduced
10 health-related quality of life (HRQoL) (Morris et al., 2013). Additionally,
11 caregivers also undergo adjustment, resulting in emotional distress, impaired
12 HRQoL and unmet needs (Buschenfeld et al., 2009).

13

14 Identifying ongoing needs and understanding how such needs may underpin
15 HRQoL could contribute to optimising HRQoL, an aim of the National stroke
16 strategy (NICE Guidelines, 2013). Further, systematic reviews regarding
17 interventions for restoring the functional ability of the upper-limb reveal
18 inconsistent effects on HRQoL (Pollock, Farmer, et al., 2014; Pulman &
19 Buckley, 2013; Pulman et al., 2013) and identify a lack of adequate focus on
20 relevant psychosocial constructs (Murray & Harrison, 2004). Directing
21 attention to unmet needs and HRQoL could theoretically help optimise
22 existing interventions (Pollock et al., 2014). However, relatively few qualitative
23 studies have specifically explored experiences associated with a dysfunctional
24 upper-limb (Barker & Brauer, 2005; Connell et al., 2014; Doyle et al., 2014).
25 Such research has suggested a disparity between acute upper and lower-limb

1 management. However, stroke survivors' ongoing needs and potential factors
2 for limited efficacy of current upper-limb rehabilitation remain unexplored.

3

4 Research regarding caregivers' role also indicates changes in role and
5 adjustment to post-stroke life occur (Bulley et al., 2010; Buschenfeld et al.,
6 2009). However, the contribution of the upper-limb to these constructs has not
7 been fully examined. Indeed, no qualitative studies have specifically explored
8 caregivers' experiences pertaining to the dysfunctional upper-limb, despite
9 caregivers ascribing relative importance to upper-limb recovery (Pollock et al.,
10 2014).

11

12 Multi-perspective interviews are advocated to explore dyadic relationships on
13 the basis of accessing phenomena from more than one perspective (Kendall
14 et al., 2009) and thus also acting as a form of triangulation. No studies have
15 evaluated both caregivers and stroke survivors experiences of the
16 dysfunctional upper-limb, although caregiver and service user interviews have
17 previously examined relationships and ongoing needs in other areas (Kendall
18 et al., 2009; Jones & Morris, 2013). Therefore, given the paucity and
19 limitations of the current literature, this study aimed to investigate the
20 experiences and ongoing needs of community dwelling stroke survivors with a
21 dysfunctional upper-limb, and their caregivers.

22

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1 **Methods**

2 ***Design***

3 Phenomenology seeks to provide an account of lived experiences, thus
4 making it a suitable methodology of choice. Interpretative phenomenological
5 analysis (IPA) seeks to explore participants' perceptions of their experiences.
6 It emphasises an interpretative stance, in that the researcher aims to
7 understand the participants' experiences who is in turn trying to make sense
8 of their own experience (Smith et al., 2009). To adequately explore the
9 meaning of an experience, each account is examined in detail, focusing on
10 depth rather than breadth of data, therefore typically employing smaller
11 sample sizes (Buschenfeld et al., 2009; Connell et al., 2014; Hunt & Smith,
12 2004; Murray & Harrison, 2004).

13

14 ***Sampling and Participants***

15 Purposive sampling was used to obtain a homogenous group of participants.
16 Eight community stroke user groups in south and north London were
17 contacted. Those with an upper-limb which remained dysfunctional, were over
18 18 years of age, at least 6 months post-stroke, and with a caregiver
19 consenting to be interviewed, were provided with written information. A
20 'caregiver' was defined as a partner, family member or relative providing
21 primary care. Individuals with language or cognitive difficulties precluding
22 consent or interview participation were excluded.

23

24 ***Ethics***

25 Approval was obtained from King's College London (BDM/14/15-30).

1 ***Topic guide and Patient and Public Involvement***

2 Separate topic guides were developed for stroke survivor (Supplementary
3 Material S1) and caregiver (Supplementary Material S2) interviews, with
4 reference to IPA guidelines (Smith et al., 2009) and feedback from a Stroke
5 Patient and Family Research group. Topic guides adopted a funneled
6 structure beginning with general, and ending with specific questions (Paterson
7 & Higgs, 2005). A pilot interview, not included in the final analysis, was
8 completed.

9

10 ***Data collection***

11 Semi-structured interviews were utilised to gather in-depth data. Questions
12 were broad and open-ended, with prompts to encourage further depth (Ritchie
13 & Lewis, 2003). Interviews were conducted at participants' homes, separately,
14 but within the same visit, were audio-recorded and transcribed verbatim.
15 Interview duration ranged between 35-85 minutes and lasted on average 52
16 minutes.

17

18 ***Analysis***

19 All transcripts were analysed individually using guidance from previous IPA
20 work (Eisikovits & Koren, 2010; Smith et al., 2009). Cross-case analysis was
21 performed across all stroke survivor and carer transcripts, whereby
22 superordinate themes were abstracted into overarching master themes
23 (Supplementary Tables S3). Dyadic analysis is somewhat distinctive as it
24 requires examination of overlapping and contrasting emergent themes from

1 each pair of participants, rather than exploring such convergence and
2 divergence amongst individual participants.

3

4 **Results**

5 Findings are reported in accordance with COREQ guidelines (Tong et al.,
6 2007). Three stroke survivors and three caregivers participated. Table 1 and 2
7 highlight the respective characteristics of stroke survivors and caregivers.
8 Subjective and objective scores of upper-limb specific outcome measures are
9 presented (Supplementary Table S4).

10

11 Table 1 Stroke survivor characteristics.

12

13 Table 2 Caregiver characteristics

14

15 Three master themes emerged from data analysis (Figure 1): Finding a way
16 forwards from a poor start; The battle with the upper-limb and Relationships
17 with self and society. This is a hypothetical model and it is unclear whether
18 these processes occurred in a chronological or parallel manner.

19

20 Figure 1 Hypothetical chronological representation of master themes

21

22 ***Finding a way forwards from a poor start***

23 All participants reported a 'poor start' to upper-limb rehabilitation, with the arm
24 seemingly neglected by clinicians in favour of the lower-limb with the aim of
25 improving independence and mobility.

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“I wished they’d done more for my arm...for the arm very little...it was all concentrated on getting you walking again...so you can go to the bathroom by yourself” [Mary, stroke survivor]

Mary appeared to divert responsibility away from herself for this decision, reflecting her disappointment in the functional outcome of her arm and the loss of autonomy she perceived during her rehabilitation. A lower-limb focus was also associated with facilitation of discharge and perceived improved psychological and emotional wellbeing. This lower-limb emphasis in rehabilitation continued in the community setting and was exacerbated by perceived inadequate provision of and a delay in, receiving upper-limb interventions.

“I maintain if they had come out quicker I would have had more input on my arm” [Amy, stroke survivor]

Perceived insufficiencies in upper-limb rehabilitation were linked to dissatisfaction in functional outcomes, with associated frustration. Poor information regarding recovery potential not only detrimentally affected participation in rehabilitation, but also led to ongoing hope and perhaps unrealistic expectations of returning to ‘normal’.

“It wasn’t pointed out sufficiently...her doctor didn’t explain clearly to me that the arm was the most unlikely one to come back” [Neil, carer]

1

2 *“We have to help him so that he will be able to use his left hand as he*
3 *used to use before” [Amelie, carer]*

4

5 In some cases, this hope appeared somewhat futile and invoked emotional
6 turmoil and disappointment. Despite this, carers displayed ongoing hope in
7 the face of unchanging function, alluding to the psychological benefit of hope.

8

9 *“Hope was all on this bloody glove...it’s not going to work, it cannot*
10 *work...so I wish we hadn’t had it...so I copied that in plastic [a glove].*
11 *And let’s hope maybe she can learn to do some tricks that, that have*
12 *the air of functionality” [Neil, carer]*

13

14 These inadequacies and the associated disappointing upper-limb outcome led
15 to unmet needs. For example, caregivers desired increased independent time
16 and support to relieve the burden associated with caring, whilst stroke
17 survivors’ immediate needs focused on upper-limb recovery. Although both
18 caregivers and stroke survivors’ longer-term needs shifted towards improved
19 participation and social interaction, caregivers also desired more
20 independence and free time.

21

22 ***The battle with the upper-limb***

23 All participants viewed the dysfunctional arm negatively, largely due to
24 negative perceptions of impairments, difficulties with ADL’s and participation.

25 Stroke survivors and caregivers perceived a large degree of disembodiment

1 of the arm, which alongside the perceived 'death' of the upper-limb, appeared
2 to cause a vicious circle of passive neglect, non-use and poor function.

3

4 *"It just looks dead where she can't move it and it just hangs" [Dan,*
5 *carer]*

6

7 The persistence of stroke survivors' upper-limb impairments hindered ADL's,
8 with associated embarrassment and frustration. Within some transcripts,
9 discordance was noted in stroke survivors' ability to complete tasks of daily
10 living and their request for help with the same task, representing an internal
11 struggle between independence and dependence.

12

13 *"Yeah I can dress but if I want to button um my shirt or something I*
14 *don't button it very well... I make a mistake...it takes me time" [David,*
15 *stroke survivor]*

16

17 *"I can't button my shirts, she (carer) help me with that" [David, stroke*
18 *survivor]*

19

20 Amelie, David's caregiver, also alluded to this internal struggle. Although she
21 acknowledged David's ability to complete upper-limb tasks, she demonstrated
22 her desire to help him, perhaps further restricting his independence by
23 becoming overprotective. Upper-limb impairments also limited stroke
24 survivors' community participation with associated psychological impact.

25

1 *“You need two hands to really to turn over the music so I have to have*
2 *a music stand which means...everyone else stands and I sit...when*
3 *they stand up to sing they cast shadows all over my music...I hate*
4 *being this sort of object of people’s pity” [Mary, stroke survivor]*

5

6 Due to the increased burden of caring for stroke survivors experiencing upper-
7 limb dysfunction, caregivers reported a reduction in independence and
8 fractionation of their time, with resulting emotional impact.

9

10 *“Do the cooking, all the housework...she can just about dress herself*
11 *...the main change in role is that my timetable is now punctured in*
12 *many ways...My bubble’s being busted and I’m beginning to resent*
13 *that...I go grumpy and I’m quite a nasty piece of work...like having a*
14 *bear in the house.” [Neil, stroke survivor]*

15

16 Neil portrayed his life as a fragile balloon, vulnerable to puncture by Mary’s
17 needs and requests, whilst further demonstrating his psychological and
18 emotional burden by likening himself to a bear. Stroke survivors also
19 demonstrated a loss of independence, control and autonomy, associated with
20 significant psychological burden.

21

22 *“When you’re little you can’t do your shoe laces and then I’m an adult now*
23 *and I can’t do my shoe laces...I don’t really get frustrated or angry I s’pose it’s*
24 *just depressing” [Amy, stroke survivor]*

25

1 ***Relationships with self and society***

2 Some stroke survivors perceived a change in role from independent adult to
3 dependent, child-like personas, secondary to their upper-limb dysfunction
4 reflecting a loss of independence and autonomy.

5

6 *“I can’t dry my hair, make up, my friend does it for me...how am I*
7 *meant to dry my hair with one hand...bathing would be difficult but the*
8 *carers help me with bathing...I feel like a child” [Amy, stroke survivor]*

9

10 Other stroke survivors perceived changes in role to be synonymous with an
11 inability to achieve future goals. David portrayed an image of ‘packing’ away
12 his knives, depicting his old career and inability to work specifically in relation
13 to the function of the upper-limb, causing emotional burden and reflecting his
14 perceived lower societal position.

15

16 *“I used to be a chef. Yeah but they tell me that if I am trying to*
17 *cook...they tell me don’t do that otherwise you might cut [his arm], so I*
18 *packed all my knives, the sharpest, I packed them away” [David, stroke*
19 *survivor]*

20

21 Caregivers meanwhile perceived themselves in a service-type role, reinforcing
22 the struggle between promoting stroke survivors’ independence but also
23 becoming overprotective and thus reinforcing their dependence. Changes in
24 role also affected relationships between stroke survivors and their caregivers’.

1 Dan reported role reversal, becoming the protective adult, with his mother
2 Amy, the vulnerable dependent,

3

4 *“She can’t open jars cos she’s only got one arm and hand, she can’t even*
5 *take the lid off the milk and hold the milk at the same time...she relies on me*
6 *a lot” [Dan, carer]*

7

8 Mary and Neil’s relationship became infiltrated with guilt, resentment and
9 psychological fatigue following inequality in domestic chores and a resulting
10 power shift. Stroke survivors’ relationships within the wider society were also
11 subject to change, seemingly due to cultural stigma. Amelie and David
12 portrayed stroke as a ‘curse’ or a supernatural, contagious disease, driving
13 away family and friends.

14

15 *“Sickness is a terrible stigma among our people. I have lost every*
16 *friend. I don’t have any friends...sometimes you feel whether you have*
17 *been cursed” [David, stroke survivor]*

18

19 Abandonment resulted in sadness, isolation and restricted participation.
20 Whilst David accepted this situation, Amelie was less forgiving and
21 subsequently restricted his social interaction. Social stigma was also evident
22 in some stroke survivors’ accounts, resulting in avoidance of social occasions,
23 underpinned by an unwillingness to explain the arm’s physical appearance
24 and functionality, causing further restriction and isolation.

1 **Discussion**

2 The primary focus of this study was to investigate the experiences and
3 ongoing needs of stroke survivors with a dysfunctional upper-limb, and their
4 carers. Three master themes are discussed below.

5

6 ***Finding a way forwards from a poor start***

7 The disappointing outcome of the dysfunctional upper-limb was strongly
8 associated with negative experiences and perceptions of upper-limb
9 rehabilitation, findings corroborated by previous literature (Bulley et al., 2010;
10 Kendall et al. 2009). Similarly, a lower-limb rehabilitation emphasis, seemingly
11 reinforced by its association with early discharge, increased independence
12 and improved emotional wellbeing, was also blamed for a poor upper-limb
13 outcome. Hospital or therapist related discharge priorities (Chouliara et al.,
14 2014) may have heightened this focus, whilst a loss of participants' autonomy
15 within decision-making may have resulted in blame and deflection of
16 responsibility towards medical professionals for negative outcomes (Eccleston
17 et al., 1997). A review of general stroke rehabilitation also highlighted the
18 association of negative rehabilitation experiences with a lack of autonomy in
19 stroke survivors (Luker et al., 2015), and suggested feasible strategies such
20 as optimising communication and using collaborative goal setting to counter
21 this.

22

23 Inadequate information regarding recovery during early rehabilitation was also
24 perceived to have led to ongoing and perhaps unrealistic hope, seemingly
25 contributing to increased psychological burden, but conversely also acting as

1 a source of positivity. The role of inadequate information within the theme of
2 ongoing hope appears controversial (Maclean et al., 2000; Wiles et al., 2002),
3 perhaps because hope is ontologically defined (Paley, 2014) and exists
4 intrinsically, thus differing between and within individuals. Although previous
5 studies have reported unrealistic hope to be detrimental to recovery and
6 psychological health (Alaszewski & Wilkinson, 2015); research also
7 demonstrates dismissing all hope may negatively impact wellbeing, with hope
8 providing motivation and strength through recovery (Barker & Brauer, 2005).
9 Therefore, although adequate information is required for decision-making, the
10 likely impact of this on the development and maintenance of realistic or
11 unrealistic hope remains unclear. There may be a need for an evidence-
12 based pathway, particularly for stroke survivors with a poor prognosis, to
13 guide healthcare professionals in 1) providing sufficient information and 2) to
14 collaborate more effectively during clinical decision making with stroke
15 survivors and their carers.

16

17 All participants identified unmet needs, even many years post-stroke. Such
18 needs were largely attributed to the perceived inadequate rehabilitation
19 received post-stroke. It is unknown whether the services did indeed meet
20 required standards (NICE Guidelines, 2013) or whether services were sub-
21 optimal. Future work aligning such perceptions with service provision would
22 be insightful. Stroke survivors identified immediate needs relating to upper-
23 limb motor recovery, similar to those identified elsewhere. Indeed, Reed et al.
24 (2010) explored the experiences of stroke survivors participating in an
25 intervention comprising of exercise, goal setting and stroke specific

1 interaction. Interestingly, participants appeared to most value factors including
2 knowledge acquisition and elements which gave them the greatest amount of
3 control, in contrast to their initial aims of improving their motor function.
4 Although the generalisability of these findings was limited by response bias,
5 conclusions may be pertinent to stroke survivors experiencing a dysfunctional
6 upper-limb, given the perceived loss of control noted in this study, and the
7 significant upper-limb related psychological burden.

8

9 Caregivers identified psychological and physical support needs to reduce the
10 burden of caring and increase their independence. However, caregivers
11 appeared to feel uncomfortable divulging such information, and thereby
12 devalued their needs perhaps due to the societal norms and expectations of
13 caring (Harper & Levin, 2005). Previous research in stroke has identified
14 needs pertaining to improved support (Greenwood et al., 2009) and
15 information regarding local services (Hare et al., 2006), themes noted in this
16 study. It would seem the persistence of upper-limb dysfunction continues to
17 place a heavy burden on both stroke survivors and their carers, supporting the
18 case for improved community interventions to optimise long-term quality of life
19 for both parties.

20

21 ***The battle with the upper-limb***

22 Participants voiced negative upper-limb perceptions, resulting in
23 disembodiment of the arm and significant emotional burden. A health
24 psychology view suggests perceptions are formed by past experiences
25 (Marks et al., 2005). This reinforces the significance of participants'

1 perceptions of inadequate upper-limb rehabilitation noted in this study. The
2 impact of such negative perceptions is noted in Leventhal's model of self-
3 regulation (Leventhal et al., 2001), which provides a framework to better
4 understand how personal experiences influence perceptions of illness,
5 subsequently guiding illness related behaviours. In the current study, negative
6 perceptions appeared to impact behaviour in a vicious cycle of passive
7 neglect, non-use and poor motor function, resulting in disembodiment of the
8 limb. Given the time since stroke, such disembodiment is seemingly a
9 persisting consequence, reflecting limited physical and psychological
10 ownership of the arm and thus warranting adequate psychological strategies
11 to address this. self-management strategies could be usefully employed here,
12 with the support of carers.

13

14 The upper-limb impairments noted are similar to those reported elsewhere,
15 adversely affecting ADL's (Carod-Artal et al., 2009) and HRQoL (Nichols-
16 Larsen et al., 2005). Within the transcripts of David and Amelie, an internal
17 struggle between desiring independence and being overly-dependent or
18 becoming overprotective was identified. Stroke survivors' over-reliance on
19 their carer could be due to acceptance of a 'sick role', whereby patients are
20 exempt from normal social roles and responsibilities (Larsen & Lubkin, 2009).
21 Although such roles are normally aligned with acute conditions, variants have
22 been suggested in reference to ethnicity and age (Twaddle, 1969), perhaps
23 explaining this divergence. Previous research has attributed caregiver
24 overprotection to fear (Buschenfeld et al., 2009); however, this was not noted
25 in the current study. More noteworthy, is research suggesting ethnic

1 differences may influence caregiving behaviours and access to support
2 (Dilworth-Anderson & Gibson, 2002; Pinguart & Sörensen, 2005). The role
3 and contribution of overprotection or over dependence on determining
4 functional upper-limb outcomes is not yet clear.

5

6 Further psychological burden was engendered by losses in independence,
7 choice and autonomy for stroke survivors and caregivers, findings noted
8 previously (Salter et al., 2008). Research has also demonstrated loss of
9 control to affect selection and use of coping strategies (Sand et al., 2008),
10 whilst autonomy is posited to be one of three psychological needs within the
11 self-determination theory, in turn thought to be the basis for optimal
12 psychological functioning (Ryan & Deci, 2000). Such findings may assist
13 health professionals in their stance during decision-making and treatment
14 planning.

15

16 ***Relationships with self and society***

17 All participants reported changes in role alongside their upper-limb deficits.
18 Some stroke survivors reflected their upper-limb related dependence and loss
19 of control in a child-like persona. Although changes in role were noted in other
20 general stroke studies (Pringle et al., 2013) they did not specifically concern
21 regression to child-like roles, perhaps reflecting the highly increased
22 dependence associated with a dysfunctional upper-limb. Other stroke
23 survivors related upper-limb impairments and an inability to work to a change
24 in societal position. Previous research is in agreement on the psychological
25 impact and the possible detrimental effect of changes in role on adjustment

1 post-stroke (Sarre et al., 2014). Adjustment to the post-stroke self appears
2 significant in relation to HRQoL and seems influenced by a variety of
3 constructs including the ability to cope with losses in control or autonomy
4 (Walker et al., 2004), thus further emphasising the importance of these
5 themes. Carers also identified changes in role, perceiving themselves in
6 primarily a service-type position, causing resentment, anger and frustration.
7 Previous research has noted gender to impact such changes (Greenwood &
8 Mackenzie, 2010) although ethnic differences appeared to impact role more
9 notably in the current study.

10

11 Changes in role were also evident in relationships of caregivers and stroke
12 survivors. Some identified role reversal, whilst others reported inequity in
13 household tasks or power, engendering negative emotional reactions and
14 psychological burden. Although other studies identified similar themes,
15 benefits of mutuality and personal growth were also demonstrated
16 (Buschenfeld et al., 2009; Hunt & Smith, 2004; Murray & Harrison, 2004),
17 themes not evident in the current study. This may represent the differing ages
18 and ethnicities between samples, or the added burden of the experience of a
19 dysfunctional upper-limb. Banks & Pearson (2004) noted role changes to
20 impact family functioning, whereby members became reluctant to divulge their
21 feelings due to guilt or resentment. We identified similar findings in the carers'
22 interviews, signaling the need for adequate support and communication
23 between stroke survivors and their caregivers. This reluctance to divulge their
24 feelings may also hinder their access to support services. Relationships within
25 the community were also affected with both participants reporting restricted

1 social participation, and associated isolation, loneliness and reduced HRQoL
2 (Buschenfeld et al., 2009; McKeivitt et al., 2004).

3

4 The benefits of multi-perspective interviewing were noted within David and
5 Amelie's accounts of cultural stigma. Stroke was identified as a supernatural
6 affliction, resulting in abandonment and isolation, influencing stroke survivors'
7 HRQoL and caregivers' burden. Although relatively few studies exist on
8 stigma and stroke, similar observations have been noted (Helman, 2007;
9 Jacoby, 2002). However, authors postulated stigma is complicated by
10 discordance between participants' subjective perceptions of disability, and
11 more objective health status (Albrecht & Devlieger, 1999), themes noted in
12 this study. Caregivers and stroke survivors also identified social stigma,
13 influencing stroke survivors' participation and leading to overprotection by
14 caregivers. Given the role of information in acceptance and delineation of
15 stigma (Asbring & Narvanen, 2002) further research exploring the feasibility of
16 providing more information to both caregivers and stroke survivors may be
17 warranted.

18

19 **Limitations**

20 Homogenous samples within IPA are key in aiding transparency and
21 exploration of psychological variables. Although the sample in this study was
22 not entirely homogenous, similar levels of heterogeneity are noted within
23 similar studies (Connell et al., 2014; Jones & Morris, 2013). Additionally,
24 relative heterogeneity allowed useful discussion of ethnic differences, of value
25 given the relative paucity of research in this area. Optimising rigour is

1 imperative within qualitative research, and is primarily related to the richness
2 and depth of the data (Smith et al., 2009). Although efforts were made to
3 ensure interview data was solely related to the upper-limb, it is acknowledged
4 participants may have divulged information pertaining to more general stroke
5 experiences, therefore data should be interpreted with some degree of
6 caution. Further, although dyadic analysis was undertaken to augment the
7 perception of the phenomenon on study and efforts to explore convergence
8 and divergence between transcripts were made, it is acknowledged potentially
9 conflicting themes may have been somewhat submerged.

10

11 **Conclusions**

12 Participants voiced negative experiences of upper-limb rehabilitation.
13 Seemingly, this was associated with disappointment in upper-limb service
14 provision, including inadequate information, reduced autonomy within
15 decision-making and misplaced or persistent hope. Therefore, during acute
16 rehabilitation, healthcare professionals should be aware of motivators for
17 lower-limb rehabilitation and may wish to explore decision-making in
18 conjunction with stroke survivors and caregivers, in further detail. The
19 persistent stroke survivor and carer expectations of upper-limb recovery
20 appear intrinsically formed and may negatively affect collaborative working
21 between healthcare professionals, patients and carers, therefore highlighting
22 the important role of adequate communication and information. Lastly, the
23 experience of a dysfunctional upper-limb engenders a complex array of
24 physical and emotional needs, which appear embedded within different

1 psychological constructs, requiring adequate long-term physical and,
2 particularly, psychological community support.

3

4 Future research could explore therapists' perceptions of acute upper-limb
5 rehabilitation, the necessary components of adequate community
6 psychological support for both populations within ethnically diverse
7 populations, and post-stroke service provision across a wider sample.

8

9 **Implications for physiotherapy practice**

- 10 • Stroke survivors and their carers identified an imbalance between
11 upper and lower-limb rehabilitation during the acute phase of recovery.
12 This was perceived to impact physical and psychological function and
13 ongoing perceptions of the limb, resulting in ongoing needs, particularly
14 community-based support.
- 15
- 16 • Loss of autonomy or control during early upper-limb rehabilitation and
17 within decision making may detrimentally affect stroke survivors'
18 experience of rehabilitation. Healthcare professionals may wish to
19 explore decision making during acute rehabilitation in further detail.
- 20
- 21 • Persistent high expectations of upper-limb recovery and inadequate
22 information may negatively affect collaborative working between
23 healthcare professionals and patients, necessitating adequate and
24 timely information and communication.

25

1 **References**

- 2
- 3 Alaszewski, A., & Wilkinson, I. (2015). The paradox of hope for working age
4 adults recovering from stroke. *Health 19*, 172-187.
- 5 Albrecht, G., & Devlieger, P. J. (1999). The disability paradox: high quality of
6 life against all odds. *Social Science & Medicine*, *48*, 977-988.
- 7 Asbring, P., & Narvanen, A.-L. (2002). Women's Experiences of Stigma in
8 Relation to Chronic Fatigue Syndrome and Fibromyalgia. *Qualitative*
9 *Health Research*, *12*, 148-160.
- 10 Banks, P., & Pearson, C. (2004). Parallel lives: younger stroke survivors and
11 their partners coping with crisis. *Sexual & Relationship Therapy*, *19*(4),
12 413-429.
- 13 Barker, R. N., & Brauer, S. G. (2005). Upper-limb recovery after stroke: the
14 stroke survivors' perspective. *Disability & Rehabilitation*, *27*(20), 1213-
15 1223.
- 16 Bulley, C., Shiels, J., Wilkie, K., & Salisbury, L. (2010). Carer experiences of
17 life after stroke -- a qualitative analysis. *Disability & Rehabilitation*,
18 *32*(17), 1406-1413. doi:10.3109/09638280903531238
- 19 Buschenfeld, K., Morris, R., & Lockwood, S. (2009). The experience of
20 partners of young stroke survivors. *Disability & Rehabilitation*, *31*(20),
21 1643-1651. doi:10.1080/09638280902736338
- 22 Carod-Artal, F. J., Trizotto, D. S., Coral, L. F., & Moreira, C. M. (2009).
23 Determinants of quality of life in Brazilian stroke survivors. *Journal of*
24 *the Neurological Sciences*, *284*, 63-68.
- 25 Chouliara, N., Fisher, R. J., Kerr, M., & Walker, M. F. (2014). Implementing
26 evidence-based stroke Early Supported Discharge services: a
27 qualitative study of challenges, facilitators and impact. *Clinical*
28 *Rehabilitation*, *28*(4), 370-377. doi:10.1177/0269215513502212
- 29 Connell, L. A., McMahon, N. E., & Adams, N. (2014). Stroke survivors'
30 experiences of somatosensory impairment after stroke: An
31 Interpretative Phenomenological Analysis. *Physiotherapy 100*(2), 150-
32 155. doi:<http://dx.doi.org/10.1016/j.physio.2013.09.003>
- 33 Dilworth-Anderson, P., & Gibson, B. E. (2002). The Cultural Influence of
34 Values, Norms, Meanings, and Perceptions in Understanding
35 Dementia in Ethnic Minorities. *Alzheimer Disease & Associated*
36 *Disorders*, *16*, S56-S63.
- 37 Doyle, S. D., Bennett, S., & Dudgeon, B. (2014). Upper-limb post-stroke
38 sensory impairments: the survivor's experience. *Disability &*
39 *Rehabilitation*, *36*(12), 993-1000.
40 doi:<http://dx.doi.org/10.3109/09638288.2013.825649>
- 41 Eccleston, C., De C. Williams, A. C., & Rogers, W. S. (1997). Patients' and
42 professionals' understandings of the causes of chronic pain: Blame,
43 responsibility and identity protection. *Social Science & Medicine*, *45*(5),
44 699-709. doi:[http://dx.doi.org/10.1016/S0277-9536\(96\)00404-2](http://dx.doi.org/10.1016/S0277-9536(96)00404-2)
- 45 Eisikovits, Z., & Koren, C. (2010). Approaches to and outcomes of dyadic
46 interview analysis. *Qual Health Res*, *20*(12), 1642-1655.
47 doi:10.1177/1049732310376520
- 48 Faria-Fortini, I., Michaelsen, S. M., Cassiano, J. G., & Teixeira-Salmela, L. F.
49 (2011). Upper extremity function in stroke subjects: Relationships

- 1 between the international classification of functioning, disability, and
2 health domains. *Journal of Hand Therapy*, 24(3), 257-265.
3 doi:<http://dx.doi.org/10.1016/j.jht.2011.01.002>
- 4 Greenwood, N., & Mackenzie, A. (2010). Informal caring for stroke survivors:
5 Meta-ethnographic review of qualitative literature. *Maturitas*, 66, 268-
6 276.
- 7 Greenwood, N., Mackenzie, A., Cloud, G. C., & Wilson, N. (2009). Informal
8 primary carers of stroke survivors living at home-challenges,
9 satisfactions and coping: A systematic review of qualitative studies.
10 *Disability & Rehabilitation*, 31(5), 337-351.
- 11 Hare, R., Rogers, H., Lester, H., McManus, R. J., & Mant, J. (2006). What do
12 stroke patients and their carers want from community services? *Family*
13 *Practice*, 23(1), 131-136. doi:10.1093/fampra/cmi098
- 14 Harper, S., & Levin, S. (2005). Family Care, Independent Living and Ethnicity.
15 *Social Policy & Society*, 4, 157-169.
- 16 Helman, C. G. (2007). *Culture, Health and Illness* (Fifth Edition ed.). London.
- 17 Hunt, D., & Smith, J. A. (2004). The personal experience of carers of stroke
18 survivors: An interpretative phenomenological analysis. *Disability and*
19 *Rehabilitation*, 26(16), 1000-1011.
20 doi:<http://dx.doi.org/10.1080/09638280410001702423>
- 21 Jacoby, A. (2002). Stigma, epilepsy and quality of life. *Epilepsy and*
22 *Behaviour*, 3, 10-20.
- 23 Jones, L., & Morris, R. (2013). Experiences of adult stroke survivors and their
24 parent carers: A qualitative study. *Clinical Rehabilitation*, 27(3), 272-
25 280. doi:<http://dx.doi.org/10.1177/0269215512455532>
- 26 Kendall, M., Murray, S. A., Carduff, E., Worth, A., Harris, F., Lloyd, A., . . .
27 Sheikh, A. (2009). Use of multiperspective qualitative interviews to
28 understand patients' and carers' beliefs, experiences, and needs. *BMJ*,
29 339, 4122 - 4128. doi:10.1136/bmj.b4122
- 30 Kwakkel, G., Kollen, B. J., van der Grond, J., & Prevo, A. J. H. (2003).
31 Probability of Regaining Dexterity in the Flaccid Upper-limb: Impact of
32 Severity of Paresis and Time Since Onset in Acute Stroke. *Stroke*,
33 34(9), 2181-2186. doi:10.1161/01.str.0000087172.16305.cd
- 34 Larsen, P. D., & Lubkin, I. M. (2009). *Chronic Illness: Impact and Intervention*
35 (Seventh ed.). London: Jones & Bartlett Learning.
- 36 Leventhal, H., Leventhal, E. A., & Cameron, L. (2001). Representations,
37 procedures and affect in illness self-regulation: A perceptual-cognitive
38 model. In *Handbook of health psychology* (pp. 19-47). New Jersey:
39 Lawrence Erlbaum Associates.
- 40 Luker, J., Lynch, E., Bernhardsson, S., Bennett, L., & Bernhardt, J. (2015).
41 Stroke survivors' Experiences of Physical Rehabilitation: A Systematic
42 Review of Qualitative Studies. *Archives of Physical Medicine &*
43 *Rehabilitation*, 96, 1698-1708.
- 44 Maclean, N., Pound, P., Wolfe, C., & Rudd, A. G. (2000). Qualitative analysis
45 of stroke patients' motivations for rehabilitation. *British Medical Journal*,
46 321, 1051-1054.
- 47 Marks, D. F., Murray, M., Evans, B., Willig, C., Woodall, C., & Sykes, C.
48 (2005). *Health psychology: Theory, research and practice* California:
49 SAGE.

- 1 McKeivitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of
2 stroke: a systematic review. *Stroke*, 35(6), 1499-1505.
3 doi:10.1161/01.STR.0000127532.64840.36
- 4 Morris, J. H., van Wijck, F., Joice, S., & Donaghy, M. (2013). Predicting health
5 related quality of life 6 months after stroke: the role of anxiety and
6 upper-limb dysfunction. *Disability & Rehabilitation*, 35(4), 291-299.
7 doi:<http://dx.doi.org/10.3109/09638288.2012.691942>
- 8 Murray, C. D., & Harrison, B. (2004). The meaning and experience of being a
9 stroke survivor: an interpretative phenomenological analysis. *Disability
10 & Rehabilitation*, 26(13), 808-816.
- 11 National Audit Office. (2010). *Progress in improving stroke care*. Retrieved
12 from London:
- 13 NICE Guidelines. (2013). Stroke rehabilitation: Long - term rehabilitation after
14 stroke. Retrieved from
15 [http://www.nice.org.uk/guidance/cg162/chapter/2-research-
16 recommendations](http://www.nice.org.uk/guidance/cg162/chapter/2-research-recommendations)
- 17 Nichols-Larsen, D. S., Clark, P. C., Zeringue, A., Greenspan, A., & Blanton, S.
18 (2005). Factors influencing stroke survivors' quality of life during
19 subacute recovery. *Stroke*, 36(7), 1480-1484.
20 doi:10.1161/01.STR.0000170706.13595.4f
- 21 Paley, J. (2014). Hope, positive illusions and palliative rehabilitation. *Progress
22 in Palliative Care*, 22(6), 358-362.
23 doi:doi:10.1179/1743291X14Y.0000000084
- 24 Paterson, M., & Higgs, J. (2005). Using Hermeneutics as a Qualitative
25 Research Approach in Professional Practice. *The Qualitative Report*,
26 10, 339-357.
- 27 Pinquart, M., & Sörensen, S. (2005). Ethnic Differences in Stressors,
28 Resources, and Psychological Outcomes of Family Caregiving: A
29 Meta-Analysis. *The Gerontologist*, 45(1), 90-106.
30 doi:10.1093/geront/45.1.90
- 31 Pollock, A., Farmer, S. E., Brady, M. C., Langhorne, P., Mead, G. E.,
32 Mehrholz, J., & van Wijck, F. (2014). Interventions for improving upper-
33 limb function after stroke. *Cochrane Database of Systematic
34 Reviews*(11). doi:10.1002/14651858.CD010820.pub2
- 35 Pollock, A., St George, B., Fenton, M., & Firkins, L. (2014). Top 10 research
36 priorities relating to life after stroke - consensus from stroke survivors,
37 caregivers, and health professionals. *International Journal of Stroke*,
38 9(3), 313-320.
- 39 Pringle, J., Drummond, J. S., & McLafferty, E. (2013). Revisioning,
40 reconnecting and revisiting: the psychosocial transition of returning
41 home from hospital following a stroke. *Disability and Rehabilitation*,
42 35(23), 1991-1999. doi:10.3109/09638288.2013.770081
- 43 Pulman, J., & Buckley, E. (2013). Assessing the efficacy of different upper-
44 limb hemiparesis interventions on improving health-related quality of
45 life in stroke patients: A systematic review. *Topics in Stroke
46 Rehabilitation*, 20(2), 171-188. doi:[http://dx.doi.org/10.1310/tsr2002-
48 171](http://dx.doi.org/10.1310/tsr2002-
47 171)
- 48 Pulman, J., Buckley, E., & Clark-Carter, D. (2013). A meta-analysis evaluating
49 the effectiveness of two different upper-limb hemiparesis interventions
50 on improving health-related quality of life following stroke. *Topics in*

- 1 *Stroke Rehabilitation*, 20(2), 189-196.
2 doi:<http://dx.doi.org/10.1310/tsr2002-189>
- 3 Reed, M., Harrington, R., Duggan, A., & Wood, V. A. (2010). Meeting stroke
4 survivors' perceived needs: a qualitative study of a community-based
5 exercise and education scheme. *Clinical Rehabilitation*, 24(1), 16-25.
6 doi:10.1177/0269215509347433
- 7 Ritchie, J., & Lewis, J. (2003). *Qualitative Research Practice: A Guide for*
8 *Social Science Students and Researchers*. London: Sage.
- 9 Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the
10 facilitation of intrinsic motivation, social development and well-being.
11 *American Psychologist*, 55, 68-78.
- 12 Salisbury, L., Wilkie, K., Bulley, C., & Shiels, J. (2010). 'After the stroke':
13 patients' and carers' experiences of healthcare after stroke in Scotland.
14 *Health and Social Care in the Community*, 18(4), 424-432.
15 doi:10.1111/j.1365-2524.2010.00917.x
- 16 Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of
17 living with stroke: a qualitative meta-synthesis. *Journal of Rehabilitation*
18 *Medicine*, 40, 595-602.
- 19 Sand, L., Strang, P., & Milberg, A. (2008). Dying cancer patients' experiences
20 of powerlessness and helplessness. *Supportive Care in Cancer*, 16(7),
21 853-862. doi:10.1007/s00520-007-0359-z
- 22 Sarre, S., Redlich, C., Tinker, A., Sadler, E., Bhalla, A., & McKeivitt, C. (2014).
23 A systematic review of qualitative studies on adjusting after stroke:
24 lessons for the study of resilience. *Disability & Rehabilitation*, 36(9),
25 716-726. doi:10.3109/09638288.2013.814724
- 26 Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative*
27 *Phenomenological Analysis*. London: Sage.
- 28 Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting
29 qualitative research (COREQ): a 32-item checklist for interviews and
30 focus groups. *International Journal for Quality in Health Care*, 19, 349-
31 357.
- 32 Twaddle, A. C. (1969). Health Decisions and Sick Role Variations: An
33 Exploration. *Journal of Health and Social Behaviour*, 10, 105-115.
- 34 Walker, J. G., Jackson, H. J., & Littlejohn, G. O. (2004). Models of adjustment
35 to chronic illness: Using the example of rheumatoid arthritis. *Clinical*
36 *Psychology Review*, 24, 461-488.
- 37 Wiles, R., Ashburn, A., Payne, S., & Murphy, C. (2002). Patients' expectations
38 of recovery following stroke: a qualitative study. *Disability &*
39 *Rehabilitation*, 24(16), 841-850.

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Table 1. Stroke survivor characteristics.

Name^a	Age (years)	Gender	Affected hand	TSS (mnths)^b
David	56	Male	Right	92
Mary	74	Female	Left	71
Amy	45	Female	Right	14

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Table 2. Caregiver characteristics.

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Name^a	Age (years)	Gender	Relationship	Employment status
Amelie	36	Female	Partner (David)	Mature Student
Neil	75	Male	Partner (Mary)	Retired
Dan	20	Male	Son (Amy)	Employed

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15 a All names are pseudonyms
16 b Time since stroke (months)

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19 Figure 1. Hypothetical chronological representation of master themes

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