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RESEARCH PAPER

Assessing the impact of upper limb disability following stroke: a qualitative enquiry using internet-based personal accounts of stroke survivors

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Abstract

Purpose: Upper limb disability following stroke may have multiple effects on the individual. Existing assessment instruments tend to focus on impairment and function and may miss other changes that are personally important. This study aimed to identify personally significant impacts of upper limb disability following stroke. **Methods:** Accounts by stroke survivors, in the form of web-based diaries (blogs) and stories, were sought using a blog search engine and in stroke-related web-sites. Thematic analysis using the World Health Organisation's International Classification of Functioning Disability and Health (ICF) was used to identify personal impacts of upper limb disability following stroke. **Results:** Ninety-nine sources from at least four countries were analysed. Many impacts were classifiable using the ICF, but a number of additional themes emerged, including emotional, cognitive and behavioural changes. Blogs and other web-based accounts were easily accessible and rich sources of data, although using them raised several methodological issues, including potential sample bias. **Conclusions:** A range of impacts was identified, some of which (such as use of information technology and alienation from the upper limb) are not addressed in current assessment instruments. They should be considered in post-stroke assessments. Blogs may help in the development of more comprehensive assessments.

Keywords

Assessment, personal significance, stroke, upper limb

History

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► Implications for Rehabilitation

- A comprehensive assessment of the upper limb following stroke should include the impact of upper limb problems on social participation, as well as associated emotional, cognitive and behavioural changes.
- Using personalised assessment instruments alongside standardised measures may help ensure that these broader domains are considered in discussions between clinicians and patients.
- Rehabilitation researchers should investigate whether and how these domains could be addressed and operationalised in standard upper limb assessment instruments.

Introduction

The effects of stroke on the upper limb are a common and significant source of long-term disability [1]. Problems such as paresis, loss of sensation, pain and spasticity in the hand, arm and shoulder can have manifold consequences in the daily lives of those affected [2]. These include a reduced capacity to carry out basic self-care tasks and to fulfil life-roles, which can affect emotional and psychological wellbeing [3,4]. Effective upper limb rehabilitation requires comprehensive assessment of these impacts. A range of assessment tools is available to gauge the effects of stroke on the individual, and numerous instruments have

been developed specifically to assess the upper limb [5–7]. Some, such as the Stroke Impact Scale [8] and the Motor Activity Log [9], are both stroke- and upper limb-specific.

However, many measures neglect the patient's view on what matters in their everyday lives [6,10], which may be very different from what clinicians think is important [11], and few capture upper limb-related problems in social participation, such as maintaining relationships and using transport [10,12,13]. Still less is known about the effects of upper limb disabilities on psychological variables such as body-image and self-esteem, although upper limb disability is associated with reduced psychological well-being at 1 year post stroke [4]. The scarcity of instruments focusing on these domains may contribute to mismatches that have been observed between objective and subjective assessments of the upper limb after stroke, e.g. patients may experience and report significant change when objective measures find little or none [14,15]. Hence, there is a need to broaden upper limb assessment instruments to give greater regard to the personal perspective of stroke survivors. This requires data regarding the personal experience of upper limb disability following stroke, but the few studies that consider this issue [11,16,17] suggest there is a need for upper limb measures that specifically address the personal consequences of stroke. Recently, Ashford et al. [18] have tried to do this using patient goal to help formulate a stroke-specific upper limb assessment measure (ArMA), but this has a purely functional focus. Much remains to be done to reflect the broader concerns of stroke survivors in upper limb assessment.

While scoping the literature in this area, we found many accounts of the impact of stroke in the form of blogs – personal diaries published on the internet. Since they first began appearing in 1996, the number of blogs has increased exponentially [19], but their potential for providing raw data for health research has only recently begun to be explored [20,21], particularly in relation to mental health [22–24]. To the best of our knowledge, they have not previously been used as data sources in the rehabilitation literature. Blogs can provide quick and easily accessible data from a geographically dispersed population, whose views are expressed freely, uninfluenced by a particular research agenda [19,20]. The use of blogs and other forms of internet-based personal accounts in research is not without its methodological and ethical challenges [21,25], but it can provide valuable insights to inform and supplement further research using more established methods. Thus, the aim of this study was to identify the personal impacts of upper limb disability following stroke, using internet-based accounts of stroke survivors. This article reports on the study, discusses the use of its novel data source, and considers implications for practice and research in upper limb assessment following stroke.

Methods

We searched for internet-based accounts of stroke survivors containing references to the personal impact of their upper limb disabilities. Relevant data were extracted and analysed using template analysis [26], in which an *a priori* framework was used to describe and categorise data, and additional themes were identified. Ethical approval for the study was not sought, since it used data already in the public domain.

Search strategy

A combination of blog search engines and searches of websites used by the population of interest has been recommended to obtain blogs and other web-based personal accounts for research [19]. We used the search engine <http://www.google.com/blog-search>, and hand-searched a range of stroke support and resource

websites. As they differed in structure, no single search algorithm was suitable for use with all websites, and so combinations and variations of several terms were used. For the blog search, the terms were stroke, arm, hand and recovery; for the search of individual stroke support and resource websites, the terms were stroke, arm, hand, recovery, report, diary, story, experience (see Section 1 of Supplementary Material for search strategy). Searches were initially conducted in December 2012, and updated in September 2013. No publication date filter was imposed, but only English language blogs were included.

Screening

Websites, e-newsletters and blogs were full-text screened by one researcher (RA) to identify sources meeting the following criteria: first-hand accounts by stroke survivors, describing any upper limb-related problems following stroke. Accounts that were exclusively concerned with the experience of the stroke itself and which made no mention of the upper limb in describing its after-effects, which might be of concern during rehabilitation, were excluded. Any duplicate webpage addresses would have been deleted but none were returned by the searches.

Data extraction

The text in each included webpage was copied and pasted into a separate document, and all documents were imported to NVivo for data extraction and analysis. Where available, data regarding the writer's sex, age, location, time since stroke and type of stroke were recorded. One researcher (LP) extracted relevant qualitative data from all sources and two others (RA and CK, who had previous experience of qualitative data collection and analysis) extracted data from a randomly selected 20% sample of the sources, to assess reliability of the process. Extraction involved highlighting relevant text, but the source documents were left intact so that context could be taken into account during analysis.

Analysis

The aim of the analysis was to identify problems associated with upper limb disability that are important for stroke survivors, and so a primarily aggregative approach was employed. We used template analysis, a form of thematic analysis in which a pre-defined framework provides initial analytical themes and codes, but new descriptive themes and patterns may also emerge [26]. The World Health Organisation's International Classification of Functioning, Disability and Health (ICF) [27] was used as the initial framework. It provides coded definitions of the many variables that constitute personal health state, and so is well-suited to identify many of the concepts that may be addressed by stroke outcome measures [28]. Data were initially coded using definitions provided in the ICF manual [27] and web-based ICF browser (<http://apps.who.int/classifications/icfbrowser/>). The ICF categories are arranged hierarchically with increasingly specific definitions provided at each level, e.g. d5 = self-care (Level 1); d520 = caring for body parts (Level 2); d5201 = caring for teeth (Level 3). In our analysis, coding was conducted to Level 3 where possible, and multiple coding was allowed for complex statements.

The analytic process was piloted by two researchers, who independently coded a sub-sample of 20 of the included data sources (LP and JF, both of whom had training and several years' experience using qualitative research methods). Each researcher coded the data using ICF definitions, and identified additional themes for relevant text that could not be coded against the ICF (e.g. emotional reactions to upper limb problems). They then met to compare findings and agree definitions for the additional

themes. The remaining sources were then analysed independently by both researchers, with additional themes being developed as necessary. ICF codings were then compared and any discrepancies resolved by discussion. The new themes and associated text extracts were also discussed, and codes further clarified and rationalised by merging or redefinition, until a final set of descriptive codes was agreed. The number of sources containing each defined theme was also recorded, as an indicator of its importance within this sample. Finally, a descriptive framework was developed that encompassed the emergent themes and identified variables that might be addressed in upper limb assessment.

Results

The study process is summarised in Figure 1. Ninety-nine sources, comprising 48 blogs and 51 personal stories in support group web-pages or online newsletters met the inclusion criteria and were included in the analysis. The web addresses of these sources are provided in Sections 1 and 2 of the Supplementary Material.

Demographic data were not available in all sources – refer Table 1 for a summary. All included sources contained statements by stroke survivors about the post-acute impact of their strokes, and 39 of them (40%) also described impacts in the acute phase.

Analysis using ICF

A total of 86 ICF categories across Levels 1, 2 and 3 were represented in the extracted text. Twenty-two were in the body function domain, two related to body structure, 48 to the activities and participation domain and 14 to environmental factors. Figure 2 illustrates the proportion of sources with material coded within each Level 1 category, grouped by domain. The figure includes coding at Level 2 and 3 by collapsing them into their Level 1 code. A full list of ICF categories used, and example quotes from sources, is provided in Sections 3 and 4, respectively, of the Supplementary Material. Structures relating to movement were most commonly identified; mobility, sensory functions and support and relationships featured in more than 30% of the sources. Many upper limb-related impacts were specified in the activities and participation domain. These included domestic life

(caring for children, pets and plants), socialising (eating out, playing cards), sports and recreation (fishing, sailing and horse-riding) and the arts (drawing, painting and – cited by seven sources – playing musical instruments). The inability to use a computer mouse – which is not specified in the ICF – was often identified as a major impact on employment, leisure and social engagement.

Additional themes

For extracted data that were not amenable to coding using the ICF, an additional 36 descriptive themes were identified (see Section 5 of the Supplementary Material for the full list, with descriptors, frequencies and examples). These were arranged under four broad thematic headings: perceptions of the affected upper limb, reactions to the disability, experiences of therapy, and recovery and adaptation to the disability. Quotes below are identified by source characteristics where available.

Perceptions of the affected limb

Objectification of the affected limb was common, with a range of terms used to describe it and express feelings towards it. Although the ICF category b1801 body image appeared related to some of these concepts, its definition did not seem rich enough to incorporate all of the experiences described. In some accounts, the limb was dismissed as ‘‘useless’’, not serving any purpose; other writers saw it as an independent entity, actively resisting their will or even behaving autonomously. In some cases, the limb was not seen as part of the person’s body at all,

Table 1. Available demographic data for sample.

Variables	Proportion of sources providing variable data	Values
Sex	89%	45 males; 44 females
Age	38%	Median 39 (range 29–82) years
Time since stroke	53%	Median 3.5 (range 0.2–20) years
Country of residence	61%	UK (27), US (28), Canada (4), Australia (1)

Figure 1. Study flowchart (nil relevant = no data specifically describing impact of upper limb disabilities found; unavailable = webpage removed between initial screening and access for data extraction).

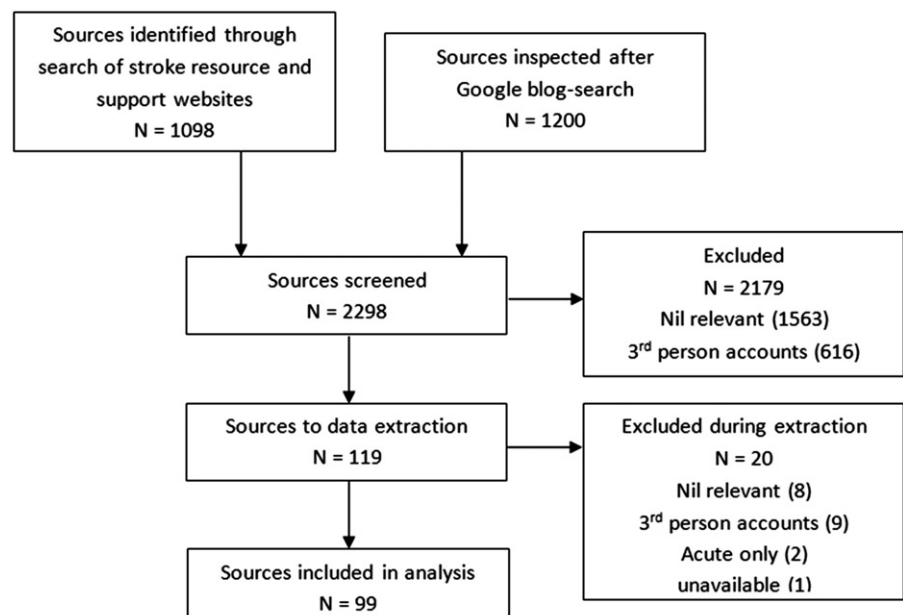
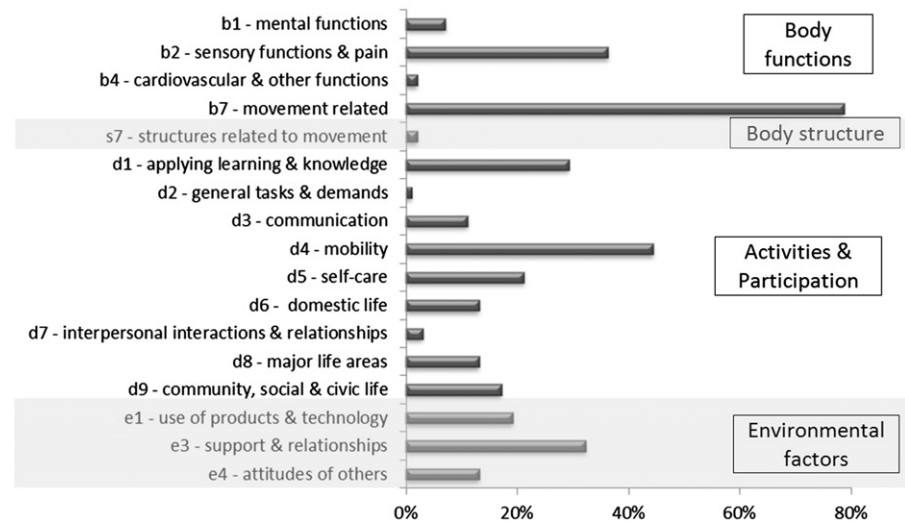


Figure 2. Proportion of sources with material coded within each of the Level 1 classifications, grouped by ICF domain.



almost alien. The descriptions were couched in emotionally loaded terms, suggesting that they held great personal significance for the individuals.

My left hand gets the blame for everything that goes wrong, but it usually deserves it. For example, I discovered that it's not closing doors properly. *Woman, 2m post-stroke*

... it is hideously slow and I have no idea where it is most of the time unless it's in direct sight, I often think I'd be better off amputating it. *34y old man, 6y post-stroke, UK*

Reactions to the disability

The impact of upper limb disabilities was expressed through a range of emotional descriptors. Frustration at not being able to accomplish simple tasks was commonly reported, along with distress at the realisation that cherished activities could no longer be engaged in.

This is one of my most frustrating tasks, getting my 'bad' hand to do some work. *54y old woman, 4y post-stroke, US*

After devoting the fifty adult years of my life to being a professional violist, you can imagine the emotional impact... I lay inert in my hospital bed completely demoralized. *Woman, US*

Concern about appearance and associated behaviour in social situations was also described. Some reported embarrassment, or a feeling they might be perceived negatively by others.

I had not eaten out since the stroke. I didn't know if I would make a fool of myself. *Woman, 1y post-stroke.*

Experiences of therapy and recovery

There was a recognition that improvements in upper limb function were often very slow and that it was easy to lose hope because of this. Maintaining a sense of personal focus and application appeared to be essential to a sense of ongoing progress. Hence,

determination and optimism were significant themes in many of the accounts of upper limb recovery. Allied to these concepts was the self-management of rehabilitation, including goal setting, creating one's own forms of therapy and monitoring and measuring progress.

I continue to play scales and exercises on the piano as therapy for my right hand in order to regain the technique I used to have. *Man, 1y post-stroke, US*

Small improvements in the movement or function of the limb – which might not be seen as important by others – could have a substantial personal impact on the individual, a symbol of hope and being on a progressive trajectory.

Another small victory I had was being able to blow dry my hair by myself. That insignificant task brought me to tears. *34y old woman, 1y post-stroke, US*

Therapy and recovery could be accompanied by intense emotional responses, including excitement at signs of progress, disappointment at the lack of it, and fear of attempting to use the limb again.

Each time I excitedly anticipated feeling those left fingers lifting and monitoring how far they were progressing. *No demographic data, US*

One of the scariest tasks for me was getting back into the kitchen. The kitchen is full of sharp and hot things. Packages demand to be opened and resealed. It is a domain of the two-handed. *Woman, US*

Adaptation to disability

For some, upper limb recovery meant striving to regain all former abilities, but many wrote of a growing acceptance of the need to adapt, both physically and psychologically. Accounts were given of learning to use the unaffected limb for tasks previously carried out by the affected limb, and this was seen as a satisfactory sign of recovery by some, though not all.

Now I am able to design and edit graphics with my left hand almost as well as I could with my right hand before the stroke. *Woman, 1y post-stroke*

Table 2. Descriptive framework of responses to upper limb disabilities.

THEME	RESPONSES		
	Emotional	Cognitive	Behavioural/physical
Perceptions of the upper limb	<ul style="list-style-type: none"> ● Revulsion 	<ul style="list-style-type: none"> ● UL as alien ● UL as bad ● UL as useless ● UL as uncooperative ● Trust/confidence in the UL 	<ul style="list-style-type: none"> ● Autonomous behaviour by UL (moving independently of the individual's will)
Reactions to the upper limb problem	<ul style="list-style-type: none"> ● Frustration ● Emotional distress ● Fear ● Despair ● Shock ● Embarrassment, shame ● Amusement 	<ul style="list-style-type: none"> ● Preferring one form of impairment or disability to another (e.g. UL amputation) ● Mental fatigue due to concentration on UL tasks ● Comparing self to others 	<ul style="list-style-type: none"> ● Hiding the effects of the impairment
Experience of recovery	<ul style="list-style-type: none"> ● Hope – hopelessness ● Disappointment ● Sadness ● Anxiety about the future ● Excitement about changes 	<ul style="list-style-type: none"> ● Psychological significance of small changes ● Beliefs and knowledge about condition and recovery ● Comparing self to others with stroke ● Determination ● Recovering a sense of autonomy-independence ● Regaining a sense of ‘‘normality’’ in use of UL ● Developing a positive sense of self ● Attitudes to therapy and therapists 	<ul style="list-style-type: none"> ● Self-management of upper limb therapy ● Monitoring changes over time ● Setting goals ● Measuring recovery ● Showing off improvements to others
Adaptation to upper limb problem	<ul style="list-style-type: none"> ● Resistance to adaptation ● Excitement about finding new ways of doing things 	<ul style="list-style-type: none"> ● Acceptance of disability ● Reframing the experience of impairment ● Valuing new experiences since stroke ● Formation of a new sense of self-identity 	<ul style="list-style-type: none"> ● Learning compensatory strategies from others ● Developing own compensatory strategies for tasks

I'm getting good at one-handed stuff but I'd rather not. *54y man, 4y post-stroke, US*

Coming to terms with the effects of upper limb disability, and apparent limitations in the capacity for physical recovery, was commonly expressed. This acceptance was often seen as a positive outcome, and was sometimes associated with a re-evaluation of what was important to the individual.

As far as I'm concerned I seem to have saved myself a lot of exhaustion and anguish by deciding my arm is 'not fit for purpose' *34y man, 6y post-stroke, UK*

I can no longer play nearly as well as I had before the stroke. However, the music I now am able to play creates the most beautiful music I have ever heard!. *No demographic data, US*

These additional themes indicated that individuals experience a broader set of upper limb-related issues than those described by the ICF alone. We arranged these in a descriptive framework encompassing emotional, cognitive and behavioural responses within each of the over-arching themes derived in the analysis (Table 2). The framework encompasses all themes identified in the thematic analysis, further details of which are given in Section 5 of the Supplementary Material. This framework was developed to provide a structured summary of personally-significant

variables that could be considered in a comprehensive upper limb assessment.

Discussion

The aim of this study was to identify personally meaningful constructs and variables that might be addressed in upper limb assessment after stroke. Whereas most existing upper limb measures focus on impairment and functional capability [5,7,13], this study suggests there are impacts in other domains that may have great significance for individuals following stroke. The study also illustrates the potential of blogs and other internet-based personal accounts as rich and accessible sources of primary qualitative data for use in health research. To the best of our knowledge, this is the first time they have been used as a data source in a rehabilitation-focused study. Our findings can inform further primary research with stroke survivors, directly addressing the impacts identified in these accounts and investigating how they could formally be incorporated into a stroke-specific outcome measure.

Template analysis using the ICF identified classifications that are particularly pertinent when assessing the impact of upper limb disability. Those that were commonly cited should be addressed in upper limb evaluations, either by incorporating them into assessment instruments or as prompts during discussion with patients. Most of the upper-limb related tasks and activities identified in the analysis are already classified within

the ICF, with the notable exception of computer mouse use. Along with the ability to use related devices such as touch screens and finger pads, this is central to participation in many aspects of contemporary life, and should be addressed in upper limb assessments.

We found a range of phenomena associated with upper limb disability that are not included in the ICF, although they may be important factors in the health state of the individual. Table 2 summarises these under headings of emotion, cognition and behaviour. Intense *emotional* responses such as joy and despair were evoked by perceptions of the upper limb and of the recovery process, often long after the stroke. The slow rates of upper limb recovery commonly experienced meant that hope, endurance and a commitment to devise one's own upper limb rehabilitation strategies were seen as particularly important. Similar reactions and preoccupations have been observed in qualitative studies of the experience of upper limb sensory impairment [16] and recovery [11] after stroke. Reported *cognitive* responses indicated that upper limb disability could have a significant impact on the individual's self-concept. For example, objectification of the affected limb and alienation from it was seen in several accounts. This can be seen as an example of the "self-body split", which emerged as a significant factor in post-stroke identity formation in a study by Ellis-Hill et al. [29]. They found that this sense of a fractured self was experienced for at least a year after the stroke; our study suggests that, for those with upper limb problems, it can persist for much longer. Other studies have found that recovery from stroke may involve the reformation of self-concept [30,31], and our study suggests that upper limb-related cognitions (for instance a growing sense of self-efficacy by increased use of the unaffected limb, or developing new interests that do not depend on the affected limb) could be important in this process. Self-concept, along with other cognitive issues identified (such as mental fatigue due to concentration on upper limb tasks, beliefs about recovery or attitudes to adaptation) may moderate reported *behavioural* responses, such as hiding the disability and adoption of compensatory strategies.

Alertness to these issues can help inform more personalised and comprehensive rehabilitation practice. Where feasible, assessment instruments should be available to measure the extent and significance of the emotional, cognitive and behavioural impacts of upper limb disability for the individual. It is neither desirable nor possible to develop instruments that consider all possible impacts, since these can vary substantially between individuals. However, personalised care planning and goal setting combined with the use of standardised validated outcome measures is far easier if those measures include the impacts that matter to patients. Some of the concepts identified in this study could be relatively straightforward to operationalise and measure using rating scales; others might be more difficult to assess. Prospective research is required to further investigate these concepts, and the links stroke survivors make between them and their upper limb disabilities. The themes derived in our analysis could inform the construction of topic guides for use in such studies. It seems likely that other significant consequences of upper limb disability remain to be explored, such as sleep disruption and expression of sexuality. Although these issues were not mentioned in the sources we analysed, they have been identified as important but often unacknowledged issues for many stroke survivors [32,33].

This study illustrates some of the strengths and limitations of using internet-based personal accounts as data sources. Accounts varied in national origin and context, thereby contributing to the generalisability of the study's findings. This is particularly important because personal factors influencing health state can

be culture-specific. However, the sample was also subject to population bias: blogging by definition requires use of an internet-connected computer, and is more likely to be engaged in by younger people [21] and those in more educated or higher socio-economic groups [23]. The restriction to English language blogs may have introduced a further cultural bias to the study. Also, those with more severe upper limb disability might be less represented in the blogosphere. However, sources also included published interviews, so computer use was not required by all informants. Nevertheless further prospective research, in which our study question is addressed directly with a more representative sample of stroke survivors, is required to both validate and further investigate our findings. A potential strength of using blogs is their capacity to track and describe changes in personal experience and cognitions over time; they are therefore ideally suited to longitudinal qualitative studies, which are uncommon in the stroke literature. Their potential in this regard remains to be explored.

The screening process was more time-consuming than in traditional literature reviews because abstracts were not available, so full texts of accounts had to be inspected to establish eligibility for inclusion. Moreover, material relating specifically to the upper-limb formed only a small part of some accounts. This reflected a limitation in the methodology, in that the writers were not responding to our study question but serving their own agendas. Conversely, it meant that the accounts were "unsolicited narratives [offering] a naturalistic entrée into the illness experience, unconstrained by time" [25, p. 353] (or, indeed, the potential influence of a researcher). The accounts were therefore governed by the writer's agenda, which was particularly important in this study, where personal significance was the focus of investigation.

This study had other potential limitations. Additional blog databases (e.g. www.blogsearchengine.org) could have been searched. However, when we analysed additional accounts obtained by the updated search, no new themes emerged, which suggested that data saturation was achieved in the study. Considering only the first few hundred hits was an arbitrary choice, but the Google blogsearch ranks sources by relevance [34], and we found those lower down the list produced increasingly less relevant data. We used limited search terms, but Google searches use both the specified terms and their synonyms [34] and so is likely to have found the most relevant blogs. Not all sources were identified by name so it is possible there was undetected duplication of sources, although all webpage addresses and personal accounts were different. Finally, resource limitations meant that only one person carried out initial screening to identify sources for inclusion, and only 20% of extracted data were independently second-checked, so some relevant material may thereby have been excluded from the analysis.

Conclusions

In addition to several specific functional limitations, this study identifies emotional responses, cognitions and behaviours that are associated with post-stroke upper limb disability and which may be important factors influencing health and well-being. These issues could be addressed during rehabilitation, and so should be included in upper limb assessment. Blogs provide a rich and feasible source of data for this study, but its findings should be used to inform further prospective qualitative research in which prospectively-identified stroke survivors are consulted directly about the issues raised. This will help establish which of the themes identified here should be incorporated into upper limb assessments, and how they might be operationalised.

Declarations of interest

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Supplementary material available online.