2017-09-14

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Thomas, CM

http://hdl.handle.net/10026.1/10072

Using Blogs to explore the lived experience of life after Stroke: 'A journey of discovery I never wanted to take.'

Caroline M. THOMAS, Rhoda ALLISON; Jos M. LATOUR

Running Head: Life after stroke: an exploration using Blogs.

Caroline M. THOMAS, BSc (Hons), MCSP
Clinical Specialist Neurophysiotherapist
Torbay and South Devon NHS Foundation Trust, Torquay, United Kingdom
School of Health Professions, Faculty of Health and Human Sciences,
Plymouth University, Plymouth, United Kingdom

Rhoda ALLISON, Clin Doc Res, MCSP;
Consultant Therapist in Stroke
Torbay and South Devon NHS Foundation Trust, Torquay, United Kingdom

Jos M.LATOUR, RN, PhD
Professor in Clinical Nursing
School of Nursing and Midwifery, Faculty of Health and Human Sciences,
Plymouth University, Plymouth, United Kingdom
School of Nursing, Midwifery and Paramedicine, Faculty of Human Science,
Curtin University, Perth, Australia

Corresponding Author:
Caroline M Thomas
Teign Ward (Stroke Unit), Newton Abbot Hospital
Newton Abbot
Devon, TQ12 4PT
United Kingdom

Email: caroline.thomas@nhs.net; Tel: 01626 324554

Twitter: @Caroline2Thomas

ABSTRACT

Aims: To explore the lived-experiences of stroke survivors as expressed in blogs and to discover the role the blogs play in the writers' lives.

Background: Stroke can be a devastating, life changing event. Previous qualitative studies tend to examine one aspect of life after stroke. As stroke often has multiple effects it is necessary to look widely at its lived-experience. New resources which can enable researchers to explore the lived-experience of stroke are blogs.

Design: Phenomenological exploration using an interpretive thematic analysis.

Methods: The internet was searched for stroke survivors' blogs (Jan - March 2016) using pre-set criteria, seeking blogs with entries over an extended period of time (>1 year). Suitable blogs were identified and codes of meaning were identified and developed into categories, sub-themes and themes.

Findings: Eight blogs were identified for analysis. Of the 40 categories, eight sub-themes were assimilated; internal dialogue, emotions, transition, stroke effects, healthcare, 'in the world', relationships, rehabilitation. Two main themes were identified related to perspectives of lived-experience; Internal relationship with 'self' and External relationship with 'the world'. Participants expressed loss and initially strove to regain their 'old' lives, their focus being recovery and independence.

Conclusion: Stroke survivors must transition from their previous life to a new and initially unwelcome way of being. Rehabilitation should respect this process and support stroke survivors as they undertake this individual journey.

Summary Statement

Why is this research or review needed?

- Blogs present a relatively untapped source of data, not readily captured by traditional means.

- Using blogs allows the researcher to take a holistic approach, allowing the stroke survivor to guide the focus of attention and priority, rather than having a predetermined area of interest.

- Blogs provide a personal and unhindered account of a lived-experience, the analysis of which can give insight and greater understanding to all involved in the care of others.

What are the key findings?

- Participant focus was on achieving function rather than on improving their physical impairments, significance being placed on the level of independence achieved.

- Participants' priorities for recovery differed from those of healthcare teams, being more life encompassing including social interaction, emotional wellbeing and life purpose.

- Participants found that the transition through acceptance to adaption to a new way of being, are crucial to a meaningful future, but achieving this is not straightforward

- Blogs can provide a detailed narrative of experience which allows the researcher to become an 'immersed observer' in the lives of those living with stroke.

How should the findings be used to influence policy/practice/research/education?

- Stroke rehabilitation services should provide a flexible response and the timing and type of support should be individualized to each stroke survivor to reflect their needs and levels of acceptance and adaption.

- Those involved in the rehabilitation of stroke survivors at all levels must endeavor not to be blinkered to needs, by their own area of expertise.

- Researchers should strive to exploit all advancing technologies and opportunities to capture the rich data available from less traditional sources.

INTRODUCTION

Stroke is a significant international issue (Feigin *et al.*, 2014). The absolute number of people having a stroke worldwide is increasing, due to an aging population. It equates to one in six people around the world having a stroke in their lifetime (World Health Organisation, 2004; Thrift *et al.*, 2017). As stroke is the greatest cause of complex disability (Kernan *et al.*, 2014; Thrift *et al.*, 2014), increasing numbers of people are living with long term effects of stroke.

Considerable research examined the effects of stroke, developing guidance for its prevention and management (Intercollegiate Stroke Working Party, 2016) but relatively limited research has explored the lived-experience of this life changing event. Creating greater insights into lived-experiences may enable those involved in their journey provide more appropriate support.

BACKGROUND

Life after Stroke

While some qualitative studies explore aspects of life after stroke such as returning to work (Wolfenden and Grace, 2009; Arlene *et al.*, 2010; Braun, 2012), others take a broader approach focusing on participant priorities, such as wellbeing or change in roles (Burton, 2000; Dowswell *et al.*, 2000; Clarke, 2003; Fallahpour *et al.*, 2013). Both approaches provide insight into the lived-experience after stroke and add to our understanding of its impact.

A systematic review of 31 qualitative studies (Luker *et al.*, 2015) investigated the experience of rehabilitation after stroke and provides detailed insight into this period of recovery. They found that patients valued being active,

autonomous and motivated but often felt bored, disempowered and frustrated. This emphasises the importance of healthcare providers working in a truly person-centred way (Intercollegiate Stroke Working Party, 2016).

An earlier thematic synthesis included 33 qualitative studies (Satink *et al.*, 2013). Thirty included studies invited participants to disclose their experience of an aspect of their lives such as work or spousal relationships, with three remaining wide in focus (Burton, 2000; Dowswell *et al.*, 2000; Murray and Harrison, 2004a). These examples suggest that researchers have found it preferable to focus, in depth, on one area of interest. The choice to narrow the focus of research may be preferable due to the variety of individual experiences of stroke and concern that depth of understanding may be lost to width of data (Mapp, 2008; Flood, 2010). Conversely, as stroke has wide ranging effects, taking an isolated aspect of life may limit consideration of contextual and concurrent factors. The 2000 Burton study remained wide in focus, interviewing six participants over at least 12 months, exploring participants' physical, social and emotional experiences. They demonstrated that recovery involved restructuring and adaption in all areas of life and highlighted that participants did not identify an end-point to recovery, placing social engagement as a higher priority than physical recovery. Dowswell et al (2000) interviewed 30 people, 13-16 months after stroke. They reflected feelings of shock and disbelief about the devastating impact of the stroke. Recovery was seen as a highly personal journey, closely linked to life contexts. Although participants reported progress, a key finding was that they rated their recovery according the degree of alignment between pre and post-stroke life. This tension created much of the discord experienced. Murray and

Harrison (2004b) interviewed 10 participants, who reflected about how their physical limitations affected their sense of self, but also prioritised emotional difficulties, sexuality, and social interaction. They emphasised the need for psychological support and the perception that level of recovery goes beyond physical improvements.

Other studies have also remained wide in their focus. Eilertsen, Kirkevold and Bjørk, (2010) explored the lived-experience of six, older women post-stroke. Using interview techniques over two years, they allowed the women to express their experience without direction. Similarly Wood (2010) used repeated interviewing over the first year to capture the experience of ten people after stroke. These studies found that participants described gradual transitions from an early focus on physical recovery, to gaining independence and a developing acceptance, allowing them to go on with 'real living'.

The difficulty of capturing the breadth of experiences whilst retaining depth is a recognised dilemma for qualitative researchers (Carter, Ritchie and Sainsbury, 2009). This difficulty could be partially overcome by collecting data frequently over an extended period. Invitations to maintain diaries may affect the writers perspective and are not always successful. Alaszewski and Potter (2006) found that only 4 out of 31 diaries were completed in their study exploring risk and uncertainty in people after stroke, presenting a limited resource. A relatively new opportunity to utilise diaries in a different way could be blogs (Wilson, Kenny and Dickson-Swift, 2015).

Blogs in Healthcare Research

Blogs, derived from 'Weblogs', (Blood, 2000) are internet based accounts which take formats such as diaries, websites and interactive communities,

commonly taking the form of personal journals. This arena is referred to as the blogosphere. 'Illness blogs' are a recognised category within the blogosphere (Heilferty, 2009) offering bloggers, (individuals that write blogs), a unique route of self-expression. Limited research has been undertaken to examine the impact of blogging on health. Merolli et al (2013) undertook a literature review examining health outcomes of using social media in chronic disease. They found that few studies investigated social media's potential, but that the impact was positive. Reported benefits were psychosocial via the emotional support offered, versus physical condition management. Chung and Kim (2008) surveyed cancer survivor bloggers. Their findings suggested that blogging aided emotional well-being and bloggers rating this benefit above information sharing and prevention.

As with any data source, blogs present benefits and challenges. Blogs can allow researchers to observe the lived-experiences of bloggers over extended periods of time without influencing the process (Prescott *et al.*, 2015; Wilson, Kenny and Dickson-Swift, 2015). Blogs used in this way are seen in chronic pain (Ressler *et al.*, 2012) and arthritis (Prescott *et al.*, 2015). As blogs are not generally written with the expectation of being used as research data, no influences are made on the topics discussed. The blogger leads the focus, dependent on *their* priorities and life contexts.

Some bloggers find their blog gives them a freedom of expression they cannot access another way, allowing voices of some inhibited people to be heard (Nardi *et al.*, 2004). Anonymity increases self-disclosure (Eastham, 2011; Rains, 2014) and the sense of privacy encourages bloggers to describe their experience more openly (Nardi *et al.*, 2004). This allows researchers to

explore intimate health issues which participants feel less able to discuss openly, such as continence issues (Saiki and Cloyes, 2014) or prostate cancer (Santos Zanchetta *et al.*, 2016).

The controlled anonymity which creates confidence can also create a challenge for the researcher. The blogger may present an 'online identity', altering how they represent themselves, perhaps censoring or embellishing what they say in a public domain, being aware of how they may be perceived (Nardi *et al.*, 2004). Blogs limit opportunities to verify understanding or explore what is 'not said' as is possible in an interview situation. These challenges are not unique to blogs as a source of data but do create limitations.

Blogs in Stroke Research

Literature searches suggest that to-date three studies use blogs of people with stroke as a resource. Poltawski *et al* (2016) explored the impact of upper limb disability and Stone (2007) and Koh *et al* (2014) investigated gender differences in expressions of life after stroke. These studies found that their results mirrored those of interview based findings, supporting the relevance of blogs as a resource. Using blogs to explore the lived-experience after stroke, without a predetermined focus, has not been undertaken and formed the methodological approach of this study.

THE STUDY

Aim

The aim is to explore how survivors and their lives transform after stroke and the role their blog plays in that process.

Design

The philosophical orientation of this explorative study was phenomenological seeking an understanding of the 'meaning of life after stroke'. The use of blogs adds a unique dimension to this paradigm. Usually there is co-creation between the participant and researcher to develop a depth of understanding (Conroy, 2003; Smythe *et al.*, 2008). However, bloggers bring their perspective in isolation, with no influence by the researcher and thus no co-creation element at this stage. To minimise the impact of researcher preconceptions, an inductive approach was used, using a thematic analysis (Braun and Clarke, 2006), allowing themes to develop from, and remain close to the data (Matua and Van Der Wal, 2015).

Sampling and Data Collection

A internet search was undertaken using the search engine 'Google'. Search terms of 'Stroke blog(s)', 'Stroke weblog(s)' and 'Stroke Story(ies) were used. A large number of hits were registered using these terms (n=55,565,900) so an advanced search filter was applied and sorted by relevance (Fig. 1). All filtered hits underwent primary review to a point where 20 consecutive hits did not relate to stroke. These hits (n=880) were then reviewed excluding duplicate, non-stroke related or moderated blogs or those with more than one contributor. Blogs that required registration to access were not included to limit the exploration to blogs entirely in the public domain. Remaining sites (n=125) underwent a detailed secondary review against the criteria (Table 1), to ensure sampling was ethical and authentic (Fig. 1). Ten blogs remained after final exclusions.

These 10 bloggers were contacted via email, requesting agreement to use their writing as a resource. Eight responded and gave consent for their blogs to be used. Two did not respond, therefore their blogs were not included in the analysis (Fig. 1). As blogs are in text format, no transcription was required. Text was transferred to a word document, grouped in codes for each participant, anonymised, dated and relevant context recorded.

Ethical Considerations

Blogs are in the public domain and are considered not to require ethical approval or consent to use them for research (Stone 2007, Eastham 2011, Wilson *et al.* 2015), however, ethical considerations remain. Blogs are private expressions within a public sphere (McCullagh 2008). Although aware that their writing can be read, bloggers may not anticipate participation in research. To protect participants' privacy in this paper, consent was gained for their use and anonymity was maintained.

Data Analysis

Thematic analysis was undertaken using text in the included blogs. Braun and Clarke (2006) described thematic analysis as seeking to establish a deeper understanding of an experience and thereby facilitate greater understanding. This can be achieved via thorough and considered development of subthemes and themes which explore the experiences but also reflect wider interactions and meaningful concepts. The process of thematic analysis was followed using five stages (Braun and Clarke, 2006).

Each blog was read twice from the first entry allowing immersion in the text and development of a naïve interpretation of each blog. The second stage involved rereading and coding. Each entry was read, in chronological order

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and codes of meaning were formulated. The codes were defined as statements around one topic which shed light on the experience of the blogger. The codes of meaning were then grouped into categories until saturation had been reached or the blog ended. The blog was then re-read to ensure that all codes of meaning had been identified and categorised. The third stage involved the development of sub-themes from these categories. Overarching themes were then created by grouping sub-themes according to their context. The fourth stage was peer checking by two senior clinicians with relevant expertise. Both independently reviewed the text examples, categories, subthemes and themes, disparities were noted and discussed until agreement on the codes and (sub)themes was achieved. In the final stage the overall meaning was explored and the synergy between the themes described.

Trustworthiness

Graneheim and Lundman (2004) and (Darawsheh (2014) suggest there are three main features of trustworthiness. Justification for the methodology adds credibility to the findings. Data was collected over a significant length of time, promoting depth of understanding and observation of change.

As the researcher is a practitioner of stroke rehabilitation this may influence data analysis, thus, a reflexive log was used to record any preconceptions observed. Each code of meaning was considered before categorisation for other possible interpretations not initially obvious from the researcher's stand point.

As there is no interaction between researcher and participant, data remains stable with no risk of inconsistency of questioning between

participants (Lowes and Prowse, 2001; Tong, Sainsbury and Craig, 2007).
Checking of context for each code of meaning was undertaken to minimise
any influence on interpretation. No limit was placed on the development of
categories, to avoid excluding data.

FINDINGS

Demographic data was obtained from participant's blogs (Table 2). From 40
categories, eight subthemes were assimilated; internal dialogue, emotions,
transition, stroke effects, healthcare, 'in the world', relationships, rehabilitation.
Categories could appear in more than one subtheme if relevant. Subthemes
reflected two main themes, Internal relationship with 'self' and External
relationship with 'the world' (Table 3). The blog itself was classified as a
bridging theme, linking areas of experience (Fig. 2).

Internal experience – 'Self'

Participants described how their stroke and recovery journey affected their
inner experience and sense of self. They described how the effects of stroke
directly impacted on their abilities and the resultant internal turmoil. They also
described changes in their experience of themselves and how this was
managed and shifted overtime (Electronic Supplementary Information 1).

Stroke effects

All participants described the immediate effects of stroke, with recovery being
the focus. All expressed limitations in relation to function, rather than
impairments, striving to be as physically independent as possible.
Independence seemed to be more significant than how 'normally' the activity
was achieved. Striving for independence seemed to be a source of motivation

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but also disappointment and despondency when it appeared unachievable; 'Independence is important – with independence comes freedom. One of the reasons I use my walker the most is that it lets me get around independently' PN5.

Communication was affected in four participants. One blogger found this a significant cause of distress and frustration. Others discussed their strategies for coping with the limitations it presented, 'talking is hard so I am sending emails to communicate with people….'PN5.

Running throughout the blogs was a desire to recover and return to pre-stroke life. In earlier entries there is a sense that if they 'put enough effort in', this was achievable. Over time the emphasis shifts towards acceptance of the chronic nature of their limitations, but without a loss of hope or ambition; '…. all exercises are cumulative and the more you do the more they add up,'PN3.

Emotions

All participants experienced a range of emotions, positive and negative. Participants tended to relate how they felt to a context, inability or improvement, rather than as a state. Relatively little was written about this topic when compared to other areas, and a subtle sense of censorship of negative feelings was evident; 'This blog is being dominated by tales of woe' PN2. Despondency with current existence was expressed by all participants, often alongside frustration with physical limitations; ' I feel like a poor imitation of a real person, exhausted, insecure, pale, drawn and I can see no way out of this for the foreseeable future' PN2. All participants seemed to express less

negative feelings over time, but life events continued to challenge the fragility of this state; 'Sometimes I feel triumphant when I can do things again.'PN4.

Internal Dialogue

Participants' internal thoughts and self-talk demonstrated their fluctuating levels of recognition and acceptance of their new way of being. It was possible to sense the internal debate and struggle between different parts of the persona wanting on one hand to accept, adapt and motivate, against other resistant, frustrated and combative parts. As time progressed there was recognition of the effect of internal dialogue and of the discomfort created by these internal conflicts. With this recognition came a desire to allow views to be balanced and reflective in nature; 'As a disabled stroke survivor, I have to remind myself to **try** before I call for help; sometimes I surprise myself with what I can do' PN6.

Transition

Individual's internal dialogues and feelings seem to play a part in the transition process as one blogger wrote: 'On bad days I can remind myself: I can deal with this feeling - the feeling that my body is a bit of a stranger to me. I am getting to know this new version of myself' PN4. Initial resentment gradually transformed into a more accepting stance. This stance did not initially seem robust or permanent but more of a state of fluctuation. This process seemed separate from external factors, aligned with, but not correlating to, physical recovery. The on-going struggle with this transition was expressed by all participants; 'I do know that life won't ever be the same – whatever happens. The stroke never goes away – I just have to figure out how to live with it' PN5. Participants seemed to be able to view their lives in a different way as

acceptance of their 'new self' grew. Over time participants started to view the future in a more positive light, beginning to recognise the irreversibility of the stroke and looking to 'make the most of it' rather than yearning to return to their pre-stroke existence. This new perspective required a new stand point, one of greater acceptance, before consideration of this new future could begin; 'I spent a lot of time trying to figure out why I had the stroke. I'm still not sure I have the answer (that I like) but rather than spending any more time wondering, it makes sense for me to get on with life' PN5.

External Experience with 'the World'

Stroke seemed to alter the participants' sense of self and although this is an internal construct, the restructuring process seemed to be affected by influential others, survivors looking to find a new frame of reference for themselves; 'When people treat you like you are handicapped at some point you start believing you are' PN3.

<u>Healthcare</u>

Although a stroke is a significant medical event, relatively little emphasis was placed by the participants on this area. There was recognition that medical input had saved their lives but emphasis was placed on frustration with 'the system'. The participants rapidly felt they were experts in their own condition and resented not being in charge or at least consulted on this aspect of their recovery; 'I don't have to work with the first provider assigned to my case, that I need to trust my instincts, and that I need to act as my own advocate….'PN6.

Relationships

Participants felt that relationships were crucial to their recovery, but were vulnerable and changing. When their roles changed, so did the roles of others around them and a process of adaption to new circumstances was required. Change in roles seems to have a profound significance for all participants. The numerous roles held; spouse, parent, friend, worker, colleague were all affected by their stroke; 'I really miss reading aloud to my kids, a lot' PN4. Participant's spouses and friends became carers and supporters and mixed emotions were evident about this change of status. Although appreciative of care and support, participants also expressed discomfort; 'I wish that I could live a life that is normal without everyone adjusting their lives for me' PN7. New relationships did not emphasis the change in role for the participants as there was no precedent for the relationship and interaction with other stroke survivors seemed to be more natural. Some bloggers found relationships with other survivors gave them a sense of comradery; 'I appreciate the encouragement I get from other stroke survivors. I'm inspired by their courage' PN8.

Rehabilitation

All participants had been involved in rehabilitation. Relationships with rehabilitation staff varied and could be double-edged. There was a positive association with rehabilitation as a link to improvement but also evidence of frustration with therapists. The therapists were perceived as having a powerful position and having conflicting priorities; 'Formal rehab ends quickly so stroke survivors need angels who gently kick butt to encourage us to recover as a person' PN8.

<u>Environment</u>

Participants reported that their difficulties were magnified by environments but tended to be critical of their own limitations rather than of their surroundings. As with acceptance, willingness to adapt environments became more evident over time but the battle to 'not let things beat me' was on-going; 'I don't resent walking aids that keep me safe'PN8.

The Blog – connecting to the self and the world

Reasons for doing the blog varied from pragmatically keeping friends and family up to date to being a cathartic process; 'I started a blog to stop having the same phone conversation many times.'PN1; 'It (the blog) should provide a good mix of self-indulgence and catharticness.'PN2.

The participants were in control of how, when and what they exposed of these experiences and seemed to have an awareness of their public audience and the responsibility of the role of the blog in others' lives; 'The reason I am doing this blog is to help people go through the journey of recovering from a stroke' PN3. All participants made references to the sense of community which they gained from sharing their blogs but also reading stroke survivors blogs, creating a support network of truly empathetic support; 'I used to think people who put their lives on the Internet were odd. Who would want to be so public? Now I can't imagine recovering without it. Suffering in isolation makes the suffering so much greater PN6.

The blog expressed their internal, private experiences, their relationship with the world and the interaction between those existences. They portray the struggle to come to terms with the developing new self and its place in the world. The participants were aware that their blogs offered a unique window

through which to share their personal experience, with the world. They not only exposed the external experiences that can be seen by others but also the inner lived-experience which is usually hidden, creating an intimate sharing of experience.

Although disclosing to others, there was also a sense of inner reflection which was created by writing the blog, a process which the bloggers seemed to find therapeutic. The blog provided answers to the bloggers own questions, a resource for themselves from which to muse and reflect about their experience. 'I have also treated it (the blog) as some form of therapy'PN2.

DISCUSSION

Stroke is usually a life changing event. Although all participants shared an experience, its manifestations were individual. Despite this, all participants seemed to demonstrate movement towards a point of acceptance of their new situation. Each took their own path but the direction of travel was to accept what had happened and begin to consider a meaningful future life. Our findings are comparable to other studies in this field (Burton, 2000; Murray and Harrison, 2004b; Williams and Murray, 2013).

Two participants started the blog very quickly post-stroke and clearly demonstrated the struggle of this transition. Other participants, started their blogs later but still expressed this trend of change. For our blogger group, with mainly younger survivors, stroke was a devastating disruption to their life plan, requiring a psychological shift to be able to transform their lives, echoing other studies findings (Salter *et al.*, 2008; Kitson *et al.*, 2013).

It is tempting to think of post-stroke life as a linear journey, a model that fits with standard healthcare services (Burton 2000). Health professionals often quantify progress as regaining physical abilities. It can be seen from these blogs that this is a narrow view and perhaps pursuing normality is not the ideal approach to take as physical recovery is not correlated to an individual's ability to create a new meaningful life for themselves (Salter *et al.*, 2008; Williams and Murray, 2013). Participants' focus was on function rather than impairments, significance being placed on level of independence. People with stroke also prioritise things such as social interaction, emotional wellbeing and life purpose (Dowswell et al., 2000; Wood, 2010).

Rochette et al (2006) suggest that stroke survivors begin to look forward in their lives when expectations are matched to the reality of their existence. It is the mismatch of hoping to regain a state that is not achievable that brings discord. Emotional well-being has been shown to be associated with acceptance, rather than severity, of a disability (Murray and Harrison, 2004b) and all participants wrestle with wishing to be able to return to their previous lives and the growing recognition that it may never happen. This flux of changing internal relationship and external experiences seems to begin to reform the perspective of the new experience (Fig. 2). As the new experience is processed in this way its position becomes more established and accepted, enabling participants to start to accept and experience living in a new way.

Adaption, described as a state and process (Williams & Murray 2013), has also been recognised as part of the psychological transitioning that creates a new normal (Rittman *et al.*, 2004; Salter *et al.*, 2008). A shift in trajectory is required if stroke is to cease being seen as a hostile invader and

integrated into normality (Faircloth *et al.*, 2004). Participants resented having to adapt their lives to match their limitations, feeling *they* should improve rather than change their situation or environment. They described this as a battle and perceived adaption as 'giving in'. Hence adaption tends to follow acceptance, the participant moving from fighting the stroke to 'living *with* it' (Wolfenden and Grace, 2009).

Factors which seemed key to successful transition echoed those of similar studies (Rochette *et al.*, 2006; Northcott and Hilari, 2011). Feeling in control of your own destiny is key to building self-confidence and moving on with life (Salter *et al.* 2008). For these participants, lack of control affected confidence, creating a sense of vulnerability, but relationships with established others were supportive and helped to create a balancing sense of security.

New relationships, especially those with other stroke survivors seemed to help develop a new perspective on life. The transition of comparing 'new self' to 'old self' is a recognised stage, often bringing internal conflict. As attention turns to comparison with others, a new perspective starts to develop (Rochette *et al.* 2006). All participants were grateful to have met other survivors, could recognise that others had greater difficulties and that they were in some sense lucky. This shift from inward to outward comparisons created balance and seemed to assist in the process of transition.

It is difficult to discern whether writing blogs actually affected the experience and recovery process of life after stroke. The blog seemed not only to act as a conduit between the internal existence and external world but was also a space for bloggers to reflect on their own experiences of a

changing sense of self. Writing blogs is a reflective process, creating an opportunity to consider changing life experiences and this may in turn have helped the participants recognise and come to terms with their new self, more readily. Uniquely, blogs allow the flow and interplay between these experiences to be shared, allowing readers to witness the relationship between public, private and self, evolving. This sharing aspect may have created a sense of additional support and recognition, a sense of not being alone on such an individual journey.

Limitations

The search strategy used may have excluded suitable blogs. Criteria limiting the format of blogs analysed may have excluded useful data. Using a small number of blogs did allow an in-depth analysis to take place over an extended period however a larger study may permit a more inclusive remit.

Although peer checking was used to review the content of categories and meanings, one researcher completed the initial coding, catagorisation and analysis of the data. This may increase risk of bias.

Bloggers are a self-selecting group and in our study tended to be younger, perhaps due to proficiency with technology. This may influence the experiences and perspectives they shared in their blogs. This group therefore may not reflect the wider stroke population, limiting generalisability of our findings. As the current generations age, acceptance and availability of technology will grow and the 'digital divide' will reduce, potentially making bloggers more reflective of the stroke population.

Conclusion

Being able to 'move on', accept and adapt to a new way of being after a stroke is crucial to a meaningful future but achieving this is not straightforward. A complex transformation of internal and external relationships and transitions occur over time, gradually allowing the 'new' experience to become more 'normal'. The participants' blogs created a way to share and reflect on this transition through which living in the present could become more vital than recovering a lost past.

<u>Implications for practice</u>

Those involved in rehabilitation after stroke must endeavour not to be blinkered by their own area of expertise. Support should be appropriate for the individual context of the person affected, recognising the required transitions of acceptance and adaption. This requires a flexibility of response which may be challenging in a world of structured processes but could simply be an openness towards survivors' needs and wishes. Raising awareness of online opportunities, such as blogs, which may offer greater access to support systems, may be part of that approach.

<u>Implications for research</u>

Although the aim of this study was to explore the lived-experience of life after stroke, much has been revealed about the use of blogs as a source of data. The detailed bloggers' narratives provide researchers with a new level of involvement and inclusion. Researchers can become truly immersed as an observer in the lives of bloggers. Being invisible, effectively 'eaves dropping' on bloggers internal reflections, researchers might reach a depth of understanding and knowledge about the experiences described, which is

otherwise hard to replicate. Access to this degree of detail and context is a valuable resource and deserves to be used in a manner that will improve the lives of those who provide it and others who share their journey.

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Table 1. Inclusion and Exclusion Criteria

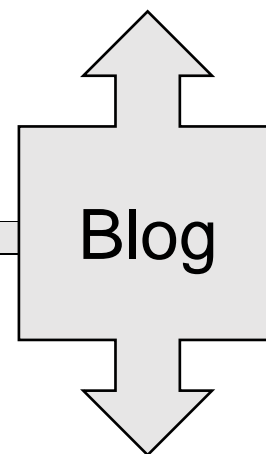| Inclusion Criteria	Exclusion Criteria
Stroke Survivor's blog	Non Stroke related blog
Over 18 years old	Under 18 years old
First Stroke event	Not first stroke event
Blog entries >1 year (>12 entries per year)	Blog entries <1 year
Written in English	Not written in English
<1 year since last entry	>1 year since last entry
Written or dictated by stroke survivor	Not written or dictated by stroke survivor
Diary style format	Commentary / information sharing format
Open Access (not password protected)	Moderated Access (password protected)

Table 2. Characteristics of Bloggers

Participant Number	Age[1]	Gender	Date of Stroke	Commencement of blog entries	Location[2]
PN1	36	F	Oct 2010	Oct 2010	UK
PN2	28	M	Dec 2005	Jan 2008	UK
PN3	68	M	Aug 2008	Nov 2014	USA
PN4	45	F	Feb 2010	May 2010	USA
PN5	49	F	Dec 2005	Feb 2009	USA
PN6	Not known	M	Dec 2008	Jan 2009	USA
PN7	45	F	March 2010	May 2011	USA
PN8	55-60	F	2004	Jan 2011	USA

F=Female; M=Male

[1] Age at time of stroke; [2] Location assumed from text references

Table 3. Categories, Subthemes and Themes

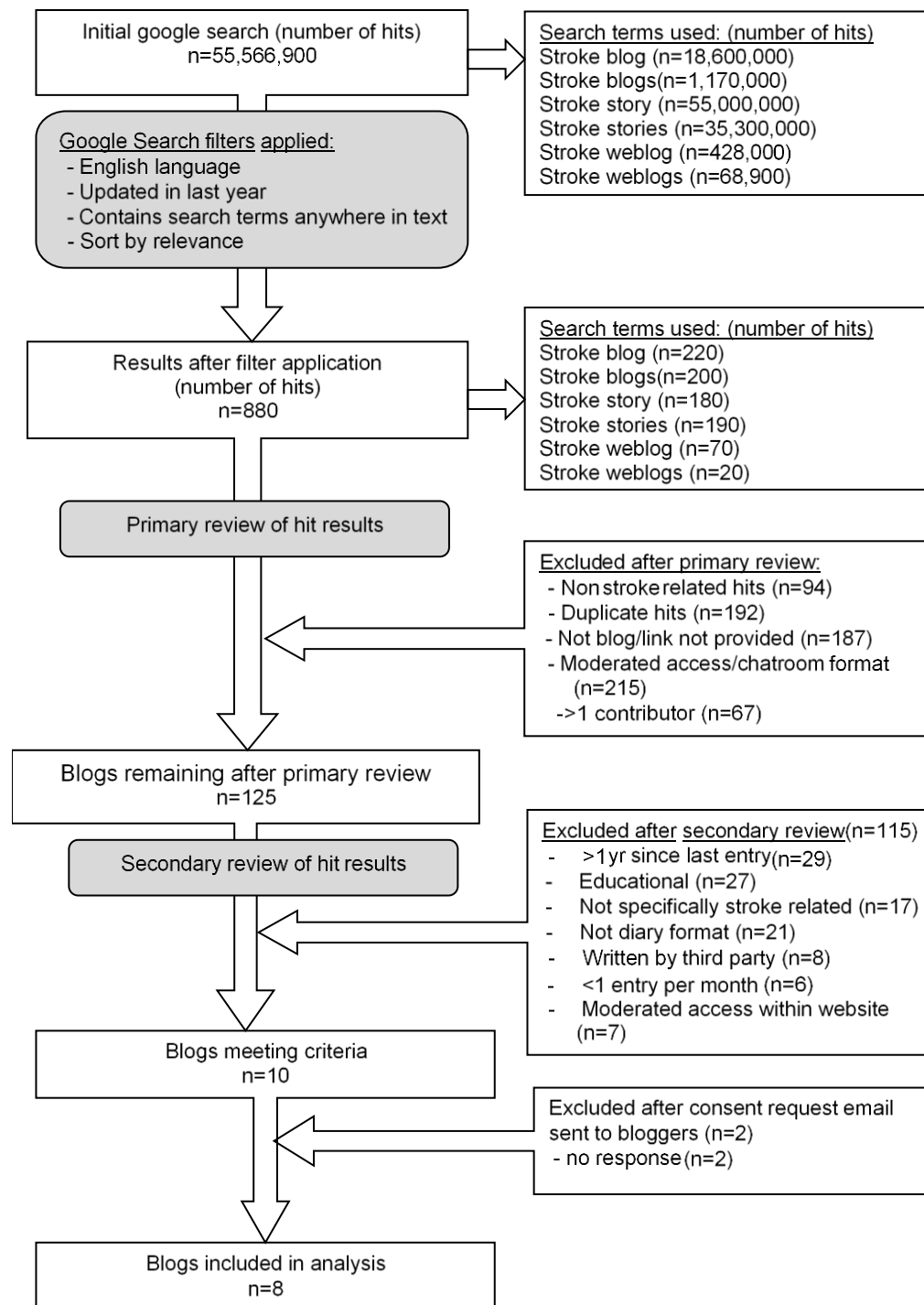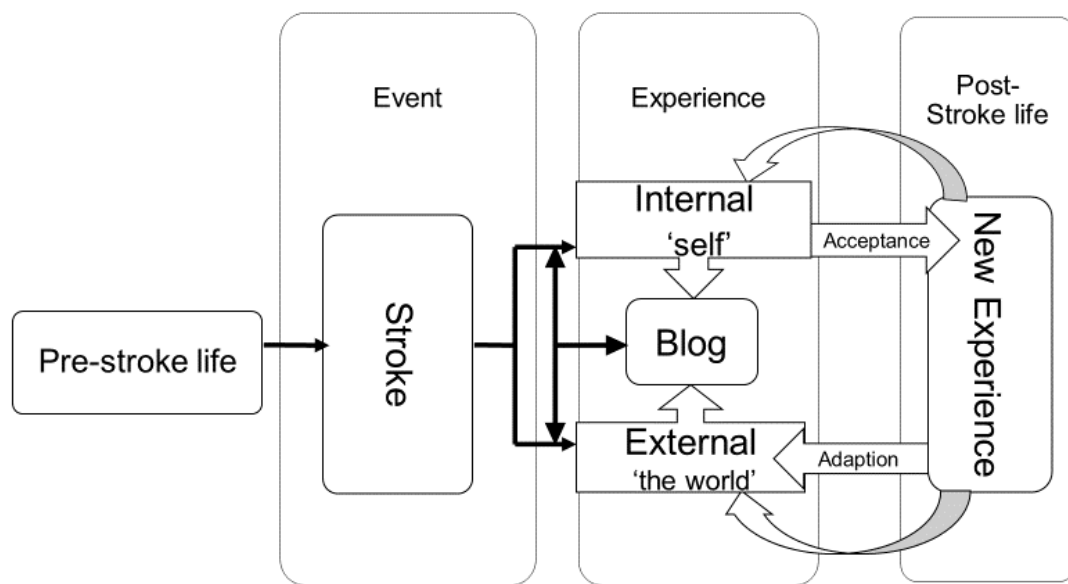| Thematic Development		
Categories	**Subthemes**	**Themes**
Comparing		
Self-belief/doubt		
Self-worth		
Expectations	**Internal dialogue**	
'Self-talk'		
Inspiration/Motivation		
Perspective		
Feelings		
Vulnerability		
Memories	**Emotions**	
Isolation		
Fears for the future		
Acceptance		
Choices		
'who I am' / Role		**Internal – 'Self'**
'Moving on'	**Transition**	(acceptance)
Measuring progress		
Self-management		
Adaption		
Mobility		
Fatigue		
Communication	**Stroke effects**	
Cognitive functions/memory		
Sensation		
Balance		**Blog**
Lack of Control		
'The system'	**Healthcare**	
Procedures		
Medication		
Independence		
Environments	**Environment**	
Isolation		
		External – 'The World'
Other people		(adaption)
Protection		
Family	**Relationships**	
Other stroke survivors		
With therapists		
Support		
Therapy		
Conflicting priorities	**Rehabilitation**	
Measuring progress		
Recovery		

Figure 1 Sampling

Figure 2 Schematic representation of life after stroke