

Stroke Association 'Life after Stroke' Outcomes Model Scoping Literature Review

What do stroke survivors and their carers report to be desirable outcomes post-stroke?

1. Introduction

There has been a renewed and increased focus within public services, in recent years, on the use of outcome measurement as a means of assessing service performance and 'success', and driving improvements in the quality of care people receive (NHS England, 2014). The 2012 White Paper 'Liberating the NHS', for example, asserted that "to achieve our ambition for world class health outcomes, the service must be focused on outcomes and the quality standards that deliver them" (p.4). This was followed by publication of the NHS Outcomes Framework, developed to "drive up quality throughout the NHS by encouraging a change in culture and behaviour focused on health outcomes not process" (Department of Health, 2013; p.2), and the development of comparable frameworks within both Public Health and Adult Social Care.

At present, there is little consensus regarding how outcomes should be defined and measured at a provider and/or service level, although there is a clear and essential need to ensure alignment with nationally-defined outcomes frameworks, such as those outlined above. Yet, it would also appear appropriate to give due consideration to the outcomes which are desired, and deemed meaningful, by other stakeholders, most notably service beneficiaries themselves.

The Stroke Association provide commissioned 'Life after Stroke' services at upwards of 350 sites across the UK, supporting stroke survivors, their carers and families in their recovery and adjustment to life after a stroke. At present, the Stroke Association is in the process of defining an Outcomes Model for their Life after Stroke services. To support the development of the model, this scoping review seeks to explore the published and grey literature to identify, examine, and bring together the existing body of evidence concerning the outcomes which stroke survivors and their carers consider most important to them post-stroke. The information identified will be subsequently used to inform development of the Stroke Association's Life after Stroke Outcomes Model, helping to ensure that the model measures,

not only outcomes of importance to public service commissioners, but also gives consideration to those outcomes which are desired by the service users themselves.

2. Methods

Several electronic bibliographic databases, shown in Table 1, were searched using combinations of the following key terms: stroke, cerebrovascular accident, self-reported, outcomes, needs, problems, difficulties, challenges, goals, experiences.

Name of databases	Type of database
Cochrane Library	Relating to evidence-based practice
Medline and PubMed	General biomedical
NHS Evidence	Relating to evidence-based health information

Table 1: Names and types of databases searched for literature.

In addition to the database searches, reference tracking was also employed, and a search of the grey literature conducted. Papers written in a language other than English were excluded, as were any papers focussing on stroke survivors and carers in countries outside of the United Kingdom. This decision was made based on the reach of the Stroke Association's commissioned services.

3. Findings

The searches revealed an absence of literature specifically concerning stroke survivor- and carer-desired outcomes post-stroke. Most of the literature identified through the searches was, instead, concerned with difficulties, problems, 'needs' or 'unmet needs' post-stroke, which, although associated with outcomes, should not be considered synonymous. While there is no universal consensus, outcomes are principally defined as "benefits or changes for intended beneficiaries" (Wainwright, 2003). This is in contrast to needs, considered in healthcare to be the "capacity to benefit from healthcare services" (Asadi-Lari et al, 2004) and unmet needs, defined as the "difference between health services deemed necessary to deal with a particular health problem and the actual services received" and which thus reflects shortcomings in the provision of care (Marshall, 2010). Notably, within the literature,

terms such as, 'needs', 'unmet needs', 'problems' and 'difficulties' were found to be frequently used synonymously, and precise working definitions were rarely provided, making it difficult to identify exactly what had been measured and was being reported.

Given the paucity of literature specifically concerning outcomes and the conceptual complexity described above, the section to follow provides an overview of the wider evidence-base regarding the needs, unmet-needs, problems and difficulties encountered by stroke survivors and their carers post-stroke (section 4), as this information may still prove of relevance to the development of the 'Life after Stroke Outcomes Model'. This is presented in two sections: the first concerned with the peer-reviewed literature and the second related to that published in the form of commissioned reports and case studies.

4. Needs, unmet-needs and difficulties post-stroke

4.1. Peer Reviewed Literature

The searches identified six peer-reviewed papers which looked directly at the needs, unmet needs and difficulties experienced and reported by stroke survivors and/or stroke carers. The findings of each of these papers are summarised below, providing a clear and complete description of the self-reported needs, unmet needs, difficulties and problems identified.

The UK Stroke Survivor Needs Survey conducted by McKeivitt *et al* (2011) collected information about the kinds of needs that people with stroke have in the long-term, the number of people with different types of needs after stroke, and how many of these needs are not met by existing services. Community-dwelling stroke survivors were sampled from those participating in the South London Stroke Register, the Oxford Vascular Study and from stroke survivors registered with a general practice involved in the General Medical Council General Practice Research Framework (a network of general practices engaged in clinical and health research). All participants were one to five years post-stroke and were invited to complete the purposefully developed 'UK Stroke Survivor Needs Survey'.

Just under half (49%) of all respondents reported one or more unmet needs. The number of unmet needs per person ranged from 1 to 13, but the average number per person was 3 unmet needs.

Just over half (54%) of those with unmet needs reported the need for more stroke specific information. There were also other areas in which people felt they required further

information including; diet (37% wanted more information), holidays for people with a disability (21%), benefits and how to get them (16%), aids and adaptations for the home (15%), and advice about driving (12%).

Over a third (38%) of the stroke survivors discussed experiencing emotional problems following the stroke, 73% of these reported not receiving the help they needed for this. Further, just over half (52%) experienced fatigue since the stroke, 43% of whom said that they did not receive the help they desired.

The Greater Manchester Stroke Assessment Tool (Rothwell *et al*, 2013) was devised to provide a needs assessment tool for use within a 6 month post-stroke review. During the pilot phase, 137 reviews were completed by the Stroke Association's Information, Advice and Support Co-ordinators which in total identified 464 unmet needs. The number of unmet needs per review varied greatly from 0 to 14, with stroke survivors reporting an average of 3 unmet needs.

Over one third (34%) of all service users experienced unmet needs relating to fatigue, whilst around a quarter (26%) had unmet needs in the areas of memory, concentration and attention, secondary prevention (non-lifestyle) (22%), and depression (19%). The areas of fatigue, memory, concentration and attention, secondary prevention (non-lifestyle), depression and benefits and finances accounted for over one third (35%) of all unmet needs identified by the reviews. These findings, particularly those pertaining to fatigue and emotional difficulties, would appear to be consistent with those of the unmet needs survey described above.

As part of their NIHR Programme Grant '**Modelling, evaluating and implementing cost-effective services to reduce the impact of stroke**', Wolfe *et al* (2014) completed a qualitative interview study assessing patients' and carers' perceptions of long-term needs post-stroke. Patients were recruited using the South London Stroke Register and were purposively selected to represent different time points post-stroke (1-11 years) and a range of age, ethnic groups, levels of disability and living conditions. Data from 35 qualitative interviews with stroke survivors identified long-term needs related to activities of daily living, social participation, mobility aids, home adaptations, housing, financial support, rehabilitation, information and use of transport. As the report notes, for those participants who experienced additional health issues, the long-term needs identified were not necessarily attributable to the stroke.

Murray *et al* (2003a) conducted a review of the qualitative literature which aimed to identify the most commonly discussed longer-term problems experienced by people who had had a stroke and their informal carers.

Twenty-three qualitative studies, involving 500 patients and 180 carers, were identified by the search methods. Most of the studies were cross-sectional, United Kingdom-based, and employed semi-structured individual interviews. The review identified 203 problem areas, which were categorised into five domains, each of which had sub-domains: social and emotional changes (sub-domains of; social, emotional, attitude to recovery, and relationships and self-perception), services (social, health, cross-cutting issues), transfer of care (process, preparation for living at home, abandonment), communication (written and verbal), and hospital experience (therapy and critical events). The largest domain was the social and emotional consequences of stroke, representing 39% of all problem areas identified within the literature.

In addition to the qualitative review, **Murray *et al* (2003b)** conducted a review of the quantitative literature to identify the types and prevalence of longer-term problems experienced by stroke survivors and their carers in the United Kingdom. From the literature search, two reviews and 27 UK-based studies were identified, which, in total, involved over 6000 stroke survivors, ranging from 1 week to 5 years post-stroke, and 3000 carers. The domains identified in their qualitative review were used during this second review.

The literature suggested that the emotional consequences of stroke are highly prevalent, ranging from 18% to 62% across different papers. One quarter of people with stroke suffered from depression more than two years post-stroke and one third suffered from anxiety in the first few weeks post-event. Depression was found to be less prominent in carers, although where it emerged, was related to patient disability. Anxiety and emotional distress was found to have affected half all carers by 6 months post-stroke and a third at 3-5 years.

Problems with social aspects of life were reported by 14%-46% of stroke survivors. At 6 months, one third of patients reported being unable to go to the shops, and by 18 months one third reported feelings of social isolation. The long-term impact on social life for carers was greater, with two thirds affected, though fewer considered themselves socially isolated (one third). After 18 months, one third of carers reported their relationship with the stroke survivor had declined since the stroke, and 18% of stroke survivors reported a worse relationship with their spouse and 25% a worse relationship with their family as a whole.

Problems with services affected between 13% and 77% of stroke survivors, and Murray *et al* reported that many service-related problems persisted at 2-3 years post-stroke. Problems

included a need for further rehabilitation input after discharge, obtaining aids and adaptations. Financial problems soon after the stroke were reported by 20% of stroke survivors, although this reduced to 8% at 2-3 years. One third of stroke survivors reported being disappointed by the support provided by social services, and a third were dissatisfied by the care provided by their GP, despite high levels of attendance.

One third of stroke survivors were disappointed by the discharge preparation, and the percentage of carers who felt unprepared for the carer role increased from 33% at discharge to 72% 9 months later.

Only 12% of patients and 19% of carers received written communication from any source in the first 4 weeks post discharge.

Other reported problems included urinary incontinence (experienced by 10% of stroke survivors) and shoulder pains (12%), which were discussed by people 2-3 years post-stroke, as well as high fall rates experienced by 36% to 73% within the first 6 months post discharge. Finally, almost a third of carers reported health complaints arising as a result of their caring role.

The 'Back to a Life After Stroke' Survey was conducted in 2008 in Scotland by the Stroke Association, Royal College of Speech and Language Therapists, and Speakability. It involved 280 stroke survivors with communication difficulties.

Unsurprisingly, given the study population, they found almost 90% of respondents had difficulties speaking, over 80% had difficulties writing, 60% had difficulties reading letters, leaflets and newspapers, 80% had difficulties using the internet and a third had difficulties understanding what people are saying.

Nearly 90% said communication difficulties had affected their independence, over 80% said their confidence had suffered as a result of their difficulties, and over 50% reported their difficulties had changed even close relationships. In addition, over 80% of respondents said their communication difficulties have had an impact on their social life. Nearly three quarters of people said that using services like health, shops and public transport was a problem once they were discharged. Finally, over 80% report that communication difficulties have adversely affected their work and 60% their income.

4.2. Reports and Case Studies

The search of the grey literature identified a number of reports and case studies of relevance to this review, many of which have been published by the Stroke Association. This literature has been analysed and the key arising themes associated with self-reported needs, unmet needs, problems and difficulties are reported below. These findings should, however, be interpreted with caution as the focus and content of such reports and case studies may have been purposely selected and principally published for reasons of awareness raising and campaigning, and therefore cannot be assumed to be fully representative of the views and experiences of the wider stroke survivor and carer population. All quotes have been taken from individual case studies.

4.2.1 Feeling of abandonment

Quite commonly in the literature, the concept of ‘abandonment’ arose with many stroke survivors describing a lack of desired input from services after they had been discharged from hospital.

“The nightmare began after I left hospital” (Feeling Overwhelmed, the Stroke Association, 2013)

*“After an initial six-week input of multi-disciplinary services – OT, physio, speech assessment – following discharge from hospital in 2005 I had nothing offered or provided. Left to get on with it!”
(Struggling to Recover, Stroke Association, 2013)*

4.2.2 Emotional difficulties

The literature described how, from the time of hospital admission, stroke survivors can experience emotional upheaval and distress as a result of the stroke.

“I could not believe the diagnosis and found it hard to come to terms with this.” (Not Just a Funny Turn, Stroke Association, 2014).

The emotional distress can continue long after they have been discharged and return home, and can affect people in different ways. Some report experiences of feelings of guilt or inadequacy *“I should have reacted to first symptoms”*; some experiences of fear *“I had severe panic attacks”*, *“each day I am still aware I could suffer a further TIA”*; and some experience feeling vulnerable *“I felt vulnerable afterwards and at the time there were no local aftercare services for*

emotional wellbeing, such as counselling, which I feel I would have benefited from". (Not Just a Funny Turn, Stroke Association, 2014)

4.2.3 The financial implications of a stroke

Stroke survivors also discussed the changes to their financial situation which occurred as a result of the stroke. Although many people are able to return to work after their stroke, there are many who cannot, which impacts on themselves and their families;

"I'm far worse off after my stroke. I had a good job before. You work hard for 20 years to achieve a comfortable standard of living, but it's taken away through no fault of your own. My wife works full-time and has to look after our young children." (Short Changed by Stroke, Stroke Association, 2012).

"Luckily I have some savings to pay for the help I need, but there are many other stroke survivors out there who don't, and who are suffering." (Short Changed by Stroke, Stroke Association, 2012)."

4.2.4 Lack of information provided

In section 3, much of the peer reviewed literature found stroke survivors to have a need for further information about stroke, and this was mirrored in the case studies;

"After TIA I had no support or advice or information...I didn't know about risk of stroke – was not told this by anyone." (Not Just a Funny Turn, Stroke Association, 2014)

As stroke survivors felt they were not given sufficient information around their stroke or TIA by the clinical staff involved in their care, they found an alternative source of information provided by the Stroke Association.

"In my NHS experience, I was not given information or advice on either stroke or TIA. I had to be self-informed and I was so grateful to find the Stroke Association website." (Not Just a Funny Turn, Stroke Association, 2014)

"I couldn't have coped without the Stroke Association – they were such a help, they were always there." (Struggling to Recover, Stroke Association, 2013)

Although some stroke survivors reported a lack of information provided to them post-stroke, several indicated that they were given the information but were not able to take it in and fully understand or comprehend what they were told;

“On the whole, I was given plenty of very helpful information. My main problem was that, having just had the TIA, I wasn’t really with it. Much of the information passed me by.” (Not Just a Funny Turn, Stroke Association, 2014)

“(I would prefer) plain speak by doctors and less jargon. Need to explain clearly to the patient what is happening to them.” (Not Just a Funny Turn, Stroke Association, 2014)

Stroke survivors also discussed the need for further information relating to secondary prevention;

“(I’d like) support in losing weight and stopping smoking rather than just telling me and then expecting me to do it.” (Not Just a Funny Turn, Stroke Association, 2014)

“(I’d like) formal in-depth classes on how to eat and exercise to reduce the risk of this happening again, or worse.” (Not Just a Funny Turn, Stroke Association, 2014)

4.2.5 Quality of service delivery

The final problem identified by stroke survivors was that related to the level of stroke-specific knowledge possessed by staff involved in their post-stroke care. Many survivors described how they perceived staff to have a lack of understanding with regards to the ‘invisible’ disabilities the stroke has left them with;

“My family and I had to fight for support, as on meeting me, I appear well. You cannot see the effects of brain damage as I am lucky to be able to speak eloquently and walk, which confused the social services. Social services need more training, education and empathy on not discriminating against invisible disabilities.” (Struggling to Recover, Stroke Association, 2013)

In addition to encountering poor knowledge concerning invisible disabilities caused by stroke, stroke survivors also reported that non-specialist staff often had poor knowledge stroke-related difficulties such as aphasia;

“Did they understand I had aphasia? No. They just seemed to think I was thick.” (Short Changed by Stroke, Stroke Association, 2012)

Stroke survivors also experienced a lack of knowledge of stroke from non-clinical staff they encountered as part of the care. One area in which the lack of knowledge was particularly discussed was regarding the Work Capability Assessment, as many people reported feelings of guilt or having their word questioned;

“He (Work capability assessor) said that I was a bit young for a stroke. It felt like he was saying I had managed to secure a diagnosis that was not accurate or truthful.” (Short Changed by Stroke, Stroke Association, 2012)

Stroke survivors also found that non-clinical staff were unaware of the wide range of affects the stroke can have including the invisible disabilities discussed previously;

“At no time did he (the assessor) address my mental state - a key issue in the problems I had been facing since my stroke.” (Short Changed by Stroke, Stroke Association, 2012)

5. Conclusion

This scoping review aimed to identify what stroke survivors and carers reported to be desirable outcomes post-stroke in order to inform development of the Stroke Association’s Life after Stroke ‘Outcomes Model. The literature searches, however, revealed a paucity of literature specifically concerning desirable outcomes post-stroke. In light of this, the scope of the review was expanded to include literature associated with the unmet needs, needs, problems and difficulties experienced by stroke survivors and their carers, utilising both peer-reviewed literature and published reports/case studies.

The literature identified demonstrated that the needs (met or unmet) and problems/difficulties experienced by stroke survivors and their carers post-stroke are diverse and varied, spanning many different domains. There was, however, found to be areas of convergence across the literature, specifically in relation to the need for: information provision; emotional support; guidance on coping with post-stroke fatigue; advice regarding aids and adaptations and support for daily living; information and advice about secondary prevention; communication support; financial guidance; opportunities for social participation; and long-term support and navigation. Further problems, while not specifically attributable to the sequelae of stroke, were also reported concerning to quality of care post-stroke, particularly in relation to a perceived absence of knowledge and awareness, among non-specialist staff, of the full impact a stroke can have on an individual and their life.

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