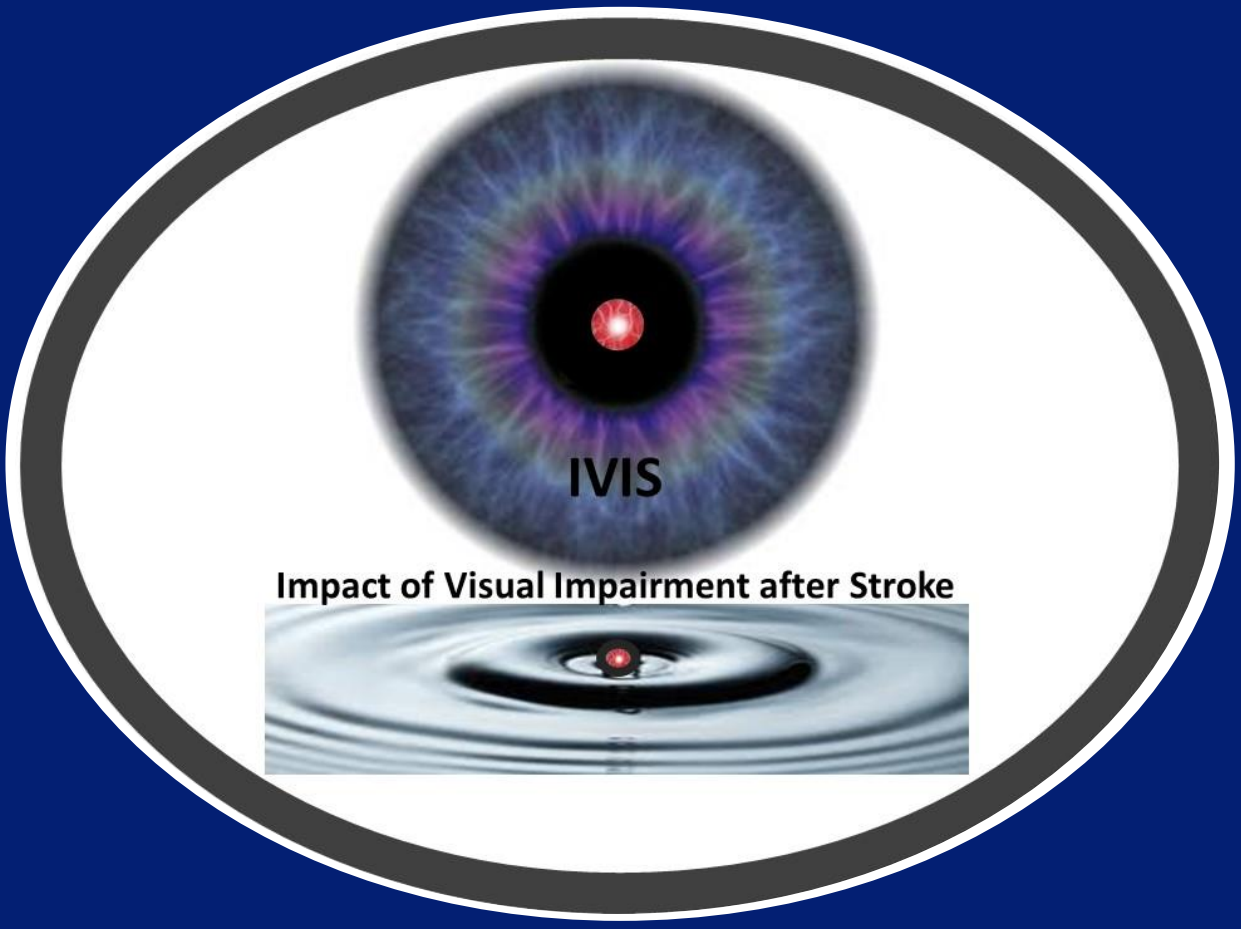
Impact of Visual Impairment after Stroke (IVIS)



Contents

Background

Stroke affects ~110000 individuals per annum in the UK and is estimated to cost the NHS almost £3bn a year (1,2). Stroke is the main cause of disability in a community setting (3). Visual impairment includes abnormalities of central and/or peripheral vision, eye movements and a variety of visual perception problems such as inattention and agnosia. It is estimated to occur in up to 70% of stroke survivors (4) and can be complex including ocular as well as cortical damage. A care issue exists in relation to visual impairment due to stroke. Vision is not routinely assessed in acute stroke settings and therefore a good understanding of the nature and extent of visual impairment is unknown in order to be able to plan care. The goal of this research programme is to critically evaluate the issue of visual impairment following stroke. This meets an urgent unmet need for information in this largely neglected area of stroke care as recently identified by the James Lind Alliance project on research priorities for stroke.

It is known from past research the types of visual impairment that may occur after stroke. Unfortunately much of this research has come from small case series. There are few large scale prospective studies. Over 2006-2010 the Vision In Stroke (VIS) study (5) recruited a large cohort of stroke survivors with visual impairment from across the UK using standardised protocols. This work confirmed that although some visual problems are easily identified, most visual problems are not detected by simply observing the individual and require questioning and assessment in order to detect their presence and subsequently make an accurate diagnosis. Thus, visual impairment following stroke may be missed or misdiagnosed (6). Visual symptoms can be poorly defined by patients and particularly where individuals have coexistent communication problems and cognitive impairments. Visual symptoms are wide ranging including blurred vision, hallucinations, diplopia and reading impairment and reported in 87% of stroke survivors with visual problems (4). There is a paucity of information on patient reported outcome measures relating visual impairment and stroke. Thus, it is unknown what symptoms are perceived to be most problematic to stroke survivors, causing impact to everyday life. It is important to ascertain this information as specific types of visual symptoms could be targeted in the future if known to be particularly problematic for patients.

There are various visual treatment options which can have a beneficial effect on vision and to general rehabilitation which should be implemented to reduce impact of visual impairment (7-9). Visual impairment can impact on quality of life through loss of confidence, impaired mobility, inability to judge distances and increased risk of falls (7,10,11). Visual impairment may impact on a patient's ability to participate in rehabilitation, to return to independent living and with an increased risk of falling (8,11,12). There is a link between poor vision, quality of life and depression in older persons (8,10-13). Visual impairment may exacerbate the effects of other impairments, leading to increased anxiety and reliance on others (8). This in turn adds strain to relationships and limits social and leisure activities of both the patient and carer (8,15). Many activities of daily living are hampered after acquiring a visual deficit, leading to increased dependence on others and long term morbidity (8,16). Long-term, visual impairment may result in considerable financial burdens placed on individuals, carers and the wider community placing a large economic cost on society (17).

For the above reasons it is important that patients with visual impairment are identified by the stroke team and appropriate referral made for vision assessment. It is equally important that the impact of visual impairment on the lives of stroke survivors is established and information is provided regarding the use of residual vision to facilitate general rehabilitation. The IVIS programme of research set out to target gaps identified by the VIS study and Cochrane systematic reviews through thorough and systematic recruitment of stroke survivors. There are public policy implications of this research. In order to plan and commission care for patients with visual impairment post stroke, it is first important to know the prevalence and incidence of visual impairment in the stroke population and what the impact of this is to the lives of these patients.

The IVIS research programme describes four phases of work. Phase 1 involved evaluation of the methods to detect impact of visual impairment along with determination of visual interventions though the conduct of two systematic reviews. Phase 2 involved determination of the nature of the problem by evaluating prevalence and incidence of visual impairment on stroke units to understand the extent of these issues and their long-term outcome. Phase 3 explored the impact of visual impairment on the lives of stroke survivors.

Phase 4 evaluated the primary research data generated in phase 2 to inform the design of a randomised controlled trial of interventions for eye movement abnormality due to stroke.

Phase 1

Systematic reviews

The IVIS programme set out to generate two systematic reviews.

Patient reported outcome measures for visual impairment after stroke: a systematic review

A variety of questionnaires exist to capture patient experiences and attitudes towards their state of health, vision and well-being. These include vision- and health-specific measures addressing quality of life and activities of daily living. There are many patient reported outcome measures that encompass vision problems which can result from other conditions and also occur after stroke. To date, little research has been conducted to address the impact of visual impairment of stroke survivors and few studies have utilised the same outcome measures (18). Thus it is not possible to compare previous studies of impact.

This review evaluated the range of outcome measures that exist to capture information on visual impairment and evaluate their applicability to the stroke population. This work was subsequently used to underpin the development of a Core Outcome Set which the intention of providing standardisation of outcome measures in future studies and trials on visual impairment following stroke. Such standardisation has the advantage of making it easier to compare, contrast and synthesise the results of trials, reduce the risk of inappropriate outcomes being measured and reduce outcome reporting bias.

The review concluded: "No instruments were developed specifically for visual impairment following stroke or involved stroke survivors in the item identification phase of instrument development. Five instruments have subsequently been used with stroke survivors. Four of these instruments (AI, NEI-VFQ, DLTV and VA LV VFQ) scored highly on positive ratings in the quality appraisal. Three are vision-specific questionnaires and intended for a broad population of individuals with visual impairment. The exception is the DLTV which was originally developed for individuals with macular degeneration. Other instruments (IVI, QoV, VQoL and VSQ) were identified in this review as having a potential application with stroke survivors with visual impairment. Of the instruments highlighted it is difficult without formal testing to recommend which would be most appropriate for use with a stroke population. However, the following instruments, AI, DLTV, VA LV VFQ and IVI have been highlighted as not be suitable for a stroke population due to question phasing and response burden. A

combination of instruments may be required to cover areas relevant to specific forms of visual impairment which are important for the population of stroke survivors with visual impairment. Further research is required to (a) consult a stroke population with different forms of visual impairment with regard to the items that they judge to be important and (b) to develop or validate appropriate instruments for use with this population." (Appendix 1)

Interventions for eye movement disorders due to acquired brain injury (Protocol) – full review in press

Eye movement disorders following stroke are typically due to damage to the neural pathways that control eye movements. Up to 68% of stroke survivors with visual symptoms have eye movement disorders (19) and these impact by causing a range of difficulties (7,8,20) including inability to maintain normal ocular alignment or move the eyes appropriately. Functional disabilities occur including loss of depth perception, reduced hand-eye coordination and reading impairment (5,6) and these may impact on effectiveness of rehabilitation therapy in regaining mobility, activities of daily living and quality of life (6,21). A recent systematic review (18) on interventions for eye movement disorders in stroke found insufficient evidence to reach conclusions about the effectiveness of interventions for patients with eye movement disorders after stroke. There was an absence of relevant evidence with a recommendation for urgent high quality research. A further recommendation was for a systematic review of non-randomised studies of interventions for eye movement disorders in patients with stroke in order to synthesise the current evidence base, to guide current practice and aid in the development of well-designed randomised controlled trials.

The purpose of this review was to directly address the recommendations of the Cochrane review (18) on interventions for eye movement disorders in stroke by undertaking a systematic review of the literature through a registered Cochrane Library review. (Appendix 2)

Core outcome measures

Following the systematic review of existing studies for review 1, we used nominal group techniques to reach consensus on use of vision-related patient-reported outcome measures

in stroke. This technique is a structured method for brainstorming with a panel of participants with relevant expertise. We followed guidance to specify a core outcome set as outlined by the COMET (Core Outcome Measures in Effectiveness Trials) initiative. Participants included clinicians and patients, open questions were used initially, we endeavoured to minimise attrition, we reported aspects of methodology and results and determined how to measure the outcomes included in the core set.

Results from this process are being finalised and the resultant core outcome sets will address:

- Screening for post-stroke visual impairment
- Full vision assessment for post-stroke visual impairment
- Vision assessment in trials of interventions for stroke-related visual impairment

Intervention options

Alongside the systematic review of existing studies for review 2, we conducted an international survey of orthoptic practice and interventions to capture information on procedures and options for visual rehabilitation for eye movement disorders. This will be used in conjunction with the results of the systematic review plus national orthoptic professional practice guidelines to develop future recommendations for best practice and inform future trial design.

This survey concluded: “Post-stroke visual impairment occurs frequently. It is evident from this international survey of orthoptists that, regardless of country, similar choices are made for use of validated vision tests in the assessment of stroke survivors. Furthermore, similar choices are made for choice of treatment options targeted to the specific visual conditions and symptoms encountered in stroke survivors. There is a clear need for core outcome measurements among various populations. The results of this survey may guide the development process to generate a core set of outcome measurements for the assessment of visual function in stroke survivors. In the knowledge that orthoptic input to the core stroke multi-disciplinary team is of benefit, the results of this international survey indicate that the role of the Orthoptist in stroke care can be undertaken at a similar level internationally.” (Appendix 3)

Phase 2

Prevalence and outcome of visual impairment

The prevalence of visual impairment amongst stroke survivors with visual symptoms is reported as up to 68% (19). Previous attempts to establish prevalence in a general stroke cohort (22) have lacked robust methodology and have included a cross section approach and case note review. Thus it remains unknown what the prevalence of visual impairment is for stroke survivors. It has not been possible to calculate incidence of visual impairment following stroke as this requires capture of visual information for all stroke survivors in a defined geographical area inclusive of all medical services from community, primary and secondary care services. Furthermore, it is recognised that some stroke survivors may never seek medical attention, for example those who only have visual deficits due to an occipital lobe stroke. Determination of prevalence of visual impairment in a stroke unit is, however, important as this is a population that typically requires intervention (4,7).

Information on prevalence is required to identify which types of visual impairment are most common following stroke, which types present with most visual symptoms and thus require prompt intervention. The data will also inform protocols for screening of visual impairment on stroke units.

It has been shown that visual impairment may exist but without presence of visual symptoms (23). Absence of symptoms in some cases relates to a mild visual impairment that can be compensated for by CNS systems. However, absence of symptoms is also seen in patients with visual impairments that are expected to be symptom producing. There appears to be a subset within the stroke population in which the brain damage results in anosognosia of these visual symptoms. The impact of visual symptoms remains to be understood and this was addressed in this IVIS study.

Recovery of visual impairment occurs at varying rates dependent on the type of visual impairment. For example, estimates indicate full recovery of visual field loss in approximately 10% of cases and partial recovery in up to 50% (24,25). Full recovery of ocular motor cranial nerve palsies in a stroke cohort has been estimated at 22% with partial recovery in approximately 43% (26). It is important to capture the natural history and long-term outcome of visual impairment due to stroke as this information will determine the

requirement for continued visual rehabilitation relevant to the different types of visual impairment and will subsequently guide the determination of service provision requirement for visual assessment and rehabilitation.

In this IVIS clinical epidemiology study, the purpose was first to determine prevalence of visual impairment by systematically evaluating all (consecutive admissions) stroke survivors within three geographically separate stroke units using validated orthoptic measures. Three distinct units (hyper-acute stroke units plus district general stroke unit) enabled representation to be drawn from different geographical areas with different demographics to ensure as representative a sample of stroke survivors as possible.

We sought to determine the prevalence of those with visual impairment in which visual symptoms are expected but absent. Further work sought to explore the potential ocular compensation mechanisms that may explain lack of symptoms before determining a neurological basis for lack of symptoms. We have determined the prevalence of those with visual symptoms as it is this group of individuals that will require targeted intervention to alleviate symptoms and reduce impact of the visual disability.

Secondly, the natural history and long-term outcome for visual impairment due to stroke has been determined by longitudinal follow-up of stroke survivors with objective diagnosis of visual impairment. By following these patients over a period of time we could ascertain how many patients only require short-term management because of natural resolution of the eye movement deficit, and which require long-term management because of persistence of eye movement deficit and resultant visual symptoms. This will guide recommendations for healthcare resources and commissioning of such services.

In our prospective study we recruited 1500 adult stroke survivors over a 15-month period. Our target population was patients in the acute phase (within 2 weeks post stroke onset) following admission to hospital with a clinical diagnosis of stroke (condition lasting longer than 24 hours). Stroke survivors identified as having visual impairment were monitored (as per national guidelines) using routine NHS appointments (to minimise drop-out rate) to determine natural history in terms of recovery of visual impairment. Full recovery was defined as a return of visual function to age-matched normative values. Partial recovery was defined as a reduction in visual symptoms and/or reduction in measurements of visual

impairment but outside normal limits of visual function. For those with limited recovery, follow-up plotted their outcome and interventions required for visual impairment.

Publication of the results of this clinical study are in development and submission stages. (Appendix 4)

Phase 3

Impact of visual impairment

Service users have played little role in the design or conduct of past research on visual impairment in stroke, which historically has been determined by clinicians (18). Recently the James Lind Alliance undertook a national survey on priorities for intervention in stroke (27). The need to establish effectiveness of interventions for visual impairment in stroke was listed within the top ten. Furthermore, the Stroke Association in liaison with the CLAHRC (Collaboration for Leadership in Applied Health Research and Care) for Greater Manchester undertook a post-stroke review pilot project to identify areas of long-term unmet need of stroke survivors. Vision was identified as an unmet need (28).

The need for patient and public involvement in research is now a requirement for conduct of research and has been found to be a positive influence on the design, development and implementation of successful research (29). Following collaboration with stroke survivors on research in recent years for the VISION trial, it is increasingly evident that the impact of visual impairment to stroke survivors has not been fully explored to reveal the extent of impact. This has been reiterated by service users who testify to a lack of information about visual impairment from stroke services in relation to rehabilitation and adaptation to the impairment (30).

In this phase of IVIS we aimed to engage widely with stroke survivors to determine impact of visual impairment to everyday life. This survey took two forms. First a survey of long-term stroke survivors was conducted to determine what their visual symptoms or difficulties were, how these impacted on their activities of daily living and quality of life, what assessments and interventions they had access to (if any) and what they perceive to be required in future research.

Second a prospective survey of stroke survivors was undertaken as they were identified during their acute stage of stroke and subsequently followed throughout their visual follow-up appointments. This process sought to capture differences between stroke services that do not offer visual assessments routinely and stroke services that do offer visual assessments. From these comparisons, differences and similarities of needs of acute and long-term stroke survivors with visual impairment could be evaluated with the potential to

guide policy development on the development and use of vision services within the stroke multidisciplinary team.

Stroke survivor views and experiences on impact of visual impairment

This study of long-term stroke survivors with visual impairment consisted of biographical narrative interviews; held with 35 long-term stroke survivors with visual impairment to ascertain their feedback on their issues. These interviews (typically 1-3 hours duration) commenced with a pre-constructed single narrative question followed by a sub-session in which additional narratives are requested relating to the sequence of topics raised and followed by non-narrative questions to explore the topics further (31). Interviews were audio-recorded, transcribed verbatim and processed twice to extract and establish themes.

The conclusions were that this study provides information about the impact of post-stroke visual impairment to quality of life through stroke survivors' accounts of their lived experiences. Improved knowledge and awareness of the visual problems that can occur due to stroke was perceived by many as being an important future change to make. Participants had not been aware that vision could be affected by a stroke and made reference to clinicians being inattentive to the possible presence of visual impairment. This potentially served to delay diagnosis of stroke in some cases. Furthermore, stroke survivors need early vision assessment after onset of stroke so that this information is available to the stroke team to influence their care provision. Early provision of visual information is reported as beneficial by stroke survivors as is post-discharge information about local support services. (Appendix 5)

Visual Impairment Following Stroke - The Impact on Quality of Life

The visual impairments caused by stroke have the potential to affect the ability of an individual to perform activities of daily living. An individual with visual impairment may also have reduced level of independence. In this phase of IVIS, we undertook a systematic review to investigate the impact on quality of life from stroke related visual impairment, using subjective patient reported outcome measures. Stroke is a complex condition; an individual can be affected by a wide range of problems, for example physical disability (hemiplegia),

communication disability (aphasia), feeding disability (dysphagia), cognitive disability, and visual impairment. It is important to establish the impact of the various components of stroke in order to evaluate interventions which are aimed at one of the specific disabilities. This review aimed to summarise the impact of stroke related visual impairment on quality of life.

The review concluded that "issues exist when extracting the specific impact of visual impairment following stroke from the impact of other sequelae of stroke, such as physical and cognitive impairments [8]. The wording of the NEI VFQ aids this task. All questions ask the participant specifically about the impact of vision. However, generic PROMs ask about the impact of their current health state on a particular aspect of health related quality of life. Consequently, the individual's current health state could include any of the sequelae of stroke. This renders it impossible to establish how much of the impact on quality of life is as a result of visual impairment. Studies which adjust for multiple factors have shown that when adjusting for confounders, participants have a poorer quality of life. This is an important consideration for researchers when choosing PROMs for future studies in this area.

Regardless of the instrument used, all studies similarly report that visual impairment following stroke results in a reduced quality of life. There are some differences in the areas of quality of life affected, relating in part to the range of instruments used and the sub-scales of these.

Eight of the eleven included studies focused on visual field loss following stroke. One of the eleven was found to assess the impact of a specific ocular motility defect (horizontal gaze palsy) occurring following stroke. There is currently no literature reporting the impact of a wider range of ocular motility defects following stroke. Due to this skew towards visual field loss and lack of studies investigating the impact of ocular motility, it was not possible to compare the effects on quality of life due to different visual impairments caused by stroke. This review highlights the need for further research into the impact of visual impairment following stroke on quality of life using appropriate vision-specific outcome measures." (Appendix 6)

Patient-report outcome measure development

Further to review an independent study was conducted to develop and, through pilot validation study of 246 participants, refine a new quality of life instrument specific to stroke-related visual impairment. The resultant 15-item questionnaire (BiVi-QoL) will proceed to full validation study for psychometric analysis. (Appendix 7)

Phase 4

RCT design

In this final summative phase of the IVIS programme, information regarding eye movement disorders was a particular focus. Phase 2 provided information on the prevalence of this particular form of visual impairment which, in turn, was used to guide the design of future intervention trials, including the feasibility of developing embedded health economic evaluations, to capture data on efficiency, effectiveness, cost-effectiveness and value for money of detecting and treating visual impairment. This follows a recommendation of the recent Cochrane systematic review which called for primary research studies in preparation for well-designed randomised controlled trials of interventions for eye movement disorders (18).

A feasibility trial for ocular motility interventions has been designed and is the subject of a current NIHR grant application.

Further outputs

In addition to the key outputs planned for each phase of the IVIS programme, the research studies evolved during the course of the programme to produce further studies and outputs to supplement the original research intentions.

A number of additional reviews of the literature were undertaken to explore related aspects of post-stroke visual impairment. Intervention efficacy was explored alongside evaluation of service provision. The health inequalities specific to post-stroke visual impairment were scrutinised and reported independently. (Appendix 8-10)

Summary

This programme of research used mixed methodology across four phases of work which were heavily interlinked throughout the 5-year duration. Key features of the programme were that the recruiting Trusts could sustain activity with appropriate throughput of patient numbers; it was a multi-centre study to ensure access to sufficient patient numbers to achieve the sample sizes required but also within a small enough geographical area to ensure standardisation and direct involvement of the core research team; the research team were multi-professional along with strong national and international collaborations.

In addition to the publications and presentations achieved thus far (see appendices) a clear dissemination strategy exists to continue reporting the key messages from the results of this research programme. Key findings to date are that:

- ✓ Two thirds of stroke survivors have visual impairment – point prevalence.
- ✓ Over half develop visual impairment as a direct consequence to their stroke – incidence.
- ✓ A range of vision interventions can be targeted to individual needs.
- ✓ Core outcome sets for assessment contribute to standardisation of assessment.
- ✓ Stroke survivors reports unmet needs with regard to visual impairment and report consistent issues with diagnosis of visual impairment, lack of information resources, and lack of public knowledge and awareness of post-stroke visual impairment.
- ✓ Quality of life and activities of daily living are impact substantially by visual impairment following stroke.
- ✓ A new patient-reported outcome measure (BiVi-Qol) may serve to improve the way in which impact on quality of life can be measured.

The results of the IVIS programme will be used to underpin national stroke and orthoptic guidelines over the forthcoming years such that clinical practice nationally can be guided by evidence.

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Web links:

VISION research unit: www.vision-research.co.uk

Think V-FAST for stroke

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Appendix 1

Patient reported outcome measures for visual impairment after stroke: a systematic review

Hepworth, L.R. Rowe F.J. Harper, R. Jarvis, K. Shipman, T. Rodgers, H. Health and Quality of Life Outcomes 2015, 13 (146), DOI: 10.1186/s12955-015-0338-x

Abstract

Purpose: The aim of this review was to identify patient reported outcome measures (PROMs) for use in research and clinical practice involving individuals with visual impairment following stroke and to evaluate their content validity against quality assessment criteria. ***Method:*** A systematic review of the literature was conducted to identify articles related to the development and/or validation of PROMS. We searched scholarly online resources and hand searched journals. Search terms included MESH terms and alternatives relating to PROMs, visual impairments and quality of life. Data were extracted relating to the development and validation of the included instruments. The quality of the development process was assessed using a modified version of a PROM quality assessment tool. ***Results:*** A total of 142 PROMs were identified, 34 vision-specific PROMs were relevant and available to be analysed in this review. Quality appraisal identified four highly rated instruments: the National Eye Institute Visual Functional Questionnaire (NEI-VFQ), Activity Inventory (AI), Daily Living Tasks Dependant on Vision (DLTV) and Veterans Affairs Low Visual Function Questionnaire (VA LV VFQ). The four instruments have only been used with either a limited number of stroke survivors or a sub-population within visual impairment following stroke. ***Conclusion:*** No instruments were identified which specifically targeted individuals with visual impairment following stroke. Further research is required to identify the items which a population of stroke survivors with visual impairment consider to be of most importance. The validation of a combination of instruments or a new instrument for use with this population is required.

Open access paper is available

Appendix 2

Patient reported outcome measures for visual impairment after stroke: a systematic review

Rowe, F.J. Noonan, C.P. Garcia-Finana, M. Dodridge, C.S. Howard, C. Jarvis, K.A. MacDiarmid, S.L. Maan, T. North, L. Rodgers, H. Cochrane Database of Systematic Reviews 2014, Issue. 9 DOI: 10.1002/14651858.CD011290

This is the protocol for a review and there is no abstract. The objectives are as follows:

The primary objective is to assess the effects of any intervention and determine the effect of timing of any intervention in the treatment of strabismus, gaze deficits and nystagmus due to acquired brain injury in order to align visual axes in primary and/or secondary gaze positions.

The secondary objectives will be to determine whether in patients with eye movement disorders due to acquired brain injury, at what time point or period, using the following interventions and comparators.

• Restitutive treatment is more effective than control, placebo, alternative treatment or no treatment in improving ocular alignment and/or motility.

• Substitutive treatment is more effective than control, placebo, alternative treatment or no treatment in improving ocular alignment and/or motility.

• Compensatory treatment is more effective than control, placebo, alternative treatment or no treatment in improving ocular alignment and/or motility.

• Pharmacological treatment is more effective than control, placebo, alternative treatment or no treatment in improving ocular alignment and/or motility.

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Appendix 3

International practice in care provision for post-stroke visual impairment

Rowe, F.J. Strabismus 2017, 25 (3) pp.112-119 DOI: 10.1080/09273972.2017.1349812

Abstract

***Purpose*:** This study sought to explore the practice of orthoptists internationally in care provision for poststroke visual impairment. ***Methods*:** Survey questions were developed and piloted with clinicians, academics, and users. Questions addressed types of visual problems, how these were identified, treated, and followed up, care pathways in use, links with other professions, and referral options. The survey was approved by the institutional ethical committee. The survey was accessed via a web link that was circulated through the International Orthoptic Association member professional organisations to orthoptists. ***Results*:** Completed electronic surveys were obtained from 299 individuals. About one-third (35.5%) of orthoptists saw patients within 2 weeks of stroke onset and over half (55.5%) by 1 month post stroke. Stroke survivors were routinely assessed by 87%; over three-quarters in eye clinics. Screening tools were used by 11%. Validated tests were used for assessment of visual acuity (76.5%), visual field (68.2%), eye movement (80.9%), binocular vision (77.9%), and visual function (55.8%). Visual problems suspected by family or professionals were high (86.6%). Typical overall follow-up period of vision care was less than 3 months. Designated care pathways for stroke survivors with visual problems were used by 56.9% of orthoptists. Information on visual impairment was provided by 85.9% of orthoptists. ***Conclusions*:** In international orthoptic practice, there is general agreement on assessment and management of visual impairment in stroke populations. More than half of orthoptists reported seeing stroke survivors within 1 month of the stroke onset, typically in eye clinics. There was a high use of validated tests of visual acuity, visual fields, ocular motility, and binocular vision. Similarly there was high use of established treatment options including prisms, occlusion, compensatory strategies, and oculomotor training, appropriately targeted at specific types of visual conditions/symptoms. This information can be used to inform choice of core outcome orthoptic measures in stroke practice.

Appendix 4

Point prevalence of visual impairment following stroke

Rowe, F. Hepworth, L. Hanna, K. Howard, C. International Journal of Stroke 2016, Vol. 11 (Suppl. 4), pp.7-8

Abstract

Introduction: Our aim is to report annual point prevalence of visual impairment in an acute adult stroke population. ***Method:*** A prospective, epidemiology study was conducted from 01/06/14 to 30/06/15 across 3 stroke units. All stroke admissions were identified by the stroke research nurses. Deaths were coded. The orthoptic research team assessed all remaining patients on the stroke unit. Patients who could not be assessed were coded for reasons why. The remaining patients had assessment of visual acuity, visual fields, ocular alignment, ocular motility, visual inattention and visual perception. ***Results:*** There were 51% males and 49% females with mean age of 73.4 (SD 13.8) years. 1289 patients were recruited: 99 died before full assessment and 169 could never be assessed. Overall 1021 patients were assessed with diagnosis. Over half were assessed at baseline. 622 could not be assessed at baseline and were subsequently reviewed. 959 underwent full visual assessment at a mean of 19.4 days. 286/1021 (28%) had normal eye exams. 735/1021 (72%) had visual impairment: 54.1% with impaired central vision, 40.8% with eye movement abnormalities, 27.2% with visual field loss, 26.3% with visual inattention and 3.9% with visual perceptual disorders. ***Conclusion:*** The point prevalence of post-stroke visual impairment in acute adult stroke survivors undertaking visual assessment is 72%. This is higher than previous reports, and highlights the need for integration of visual assessment as a core post-stroke assessment. Full visual assessment is possible for most stroke survivors by 4 days. Thus early visual assessment is feasible and important in that information can be provided on visual status and the functional significance of this to the stroke team, patients and carers.

Point prevalence and incidence of visual impairment following stroke

Rowe, F. Hepworth, L. Hanna, K. Howard, C. Investigative Ophthalmology and Visual Science 2017, Vol. 58 (8), pp.4663.

Abstract

Purpose: To report annual point prevalence and incidence of visual impairment in an acute adult stroke population. **Methods**: A prospective, epidemiology study was conducted from 1.6.14 to 30.6.15 across 3 stroke units. All stroke admissions were identified by the stroke research nurses. Deaths were coded. The orthoptic research team assessed all remaining patients on the stroke unit. Patients who could not be assessed were coded for reasons why. The remaining patients had standard clinical assessment of visual acuity, visual fields, ocular alignment, ocular motility, visual inattention and visual perception. **Results**: There were 51% males and 49% females with mean age of 73.4 (SD 13.8) years. 1291 patients were recruited: 99 died before full assessment and 169 could never be assessed. Overall 1023 patients were assessed with diagnosis. Over half were assessed at baseline. 622 could not be assessed at baseline and were subsequently reviewed. 959 underwent full visual assessment at a mean of 19.4 days. 279/1023 (28%) had normal eye exams. 744/1023 (72%) had visual impairment: 55.8% with impaired central vision, 41.7% with eye movement abnormalities, 28% with visual field loss, 27.2% with visual inattention and 4.3% with visual perceptual disorders. 75/1023 (7.3%) had visual impairment due to pre-existent causes. **Conclusions**: The point prevalence of post-stroke visual impairment in acute adult stroke survivors undertaking visual assessment is 73% with incidence of stroke-related visual impairment being 65.4%. This is higher than previous reports, and highlights the need for integration of visual assessment as a core post-stroke assessment. Full visual assessment possible for most stroke survivors by 4 days. Thus early visual assessment is feasible and important in that information can be provided on visual status and the functional significance of this to the stroke team, patients and carers.

Appendix 5

Stroke survivors' views and experiences on impact of visual impairment

Rowe, F.J. Brain and Behavior 2017, 7 (9) DOI: 10.1002/brb3.778

Abstract

Objectives: We sought to determine stroke survivors' views on impact of stroke-related visual impairment to quality of life. ***Materials and Methods:*** Stroke survivors with visual impairment, more than 1 year post stroke onset, were recruited. Semistructured biographical narrative interviews were audio-recorded and transcribed verbatim. A thematic approach to analysis of the qualitative data was adopted. Transcripts were systematically coded using NVivo10 software. ***Results:*** Thirty-five stroke survivors were interviewed across the UK: 16 females, 19 males; aged 20–75 years at stroke onset. Five qualitative themes emerged: "Formal care," "Symptoms and self," "Adaptations," "Daily life," and "Information." Where visual problems existed, they were often not immediately recognized as part of the stroke syndrome and attributed to other causes such as migraine. Many participants did not receive early vision assessment or treatment for their visual problems. Visual problems included visual field loss, double vision, and perceptual problems. Impact of visual problems included loss in confidence, being a burden to others, increased collisions/accidents, and fear of falling. They made many self-identified adaptations to compensate for visual problems: magnifiers, large print, increased lighting, use of white sticks. There was a consistent lack of support and provision of information about visual problems. ***Conclusions:*** Post-stroke visual impairment causes considerable impact to daily life which could be substantially improved by simple measures including early formal visual assessment, management and advice on adaptive strategies and self-management options. Improved education about post-stroke visual impairment for the public and clinicians could aid earlier diagnosis of visual impairments.

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Appendix 6

Visual impairment following stroke – the impact on quality of life: a systematic review

Hepworth, L.R. Rowe, F.J. Ophthalmology Research 2016, 5 (2) DOI: 10.9734/OR/2016/23272

Abstract

Background: The visual impairments caused by stroke have the potential to affect the ability of an individual to perform activities of daily living. An individual with visual impairment may also have reduced level of independence. The purpose of this review was to investigate the impact on quality of life from stroke related visual impairment, using subjective patient reported outcome measures. ***Methods:*** A systematic search of the literature was performed. The inclusion criteria required studies to have adult participants (aged 18 years or over) with a diagnosis of a visual impairment directly resulting from a stroke. Studies which included visual impairment as a result of other intracranial aetiology, were included if over half of the participants were stroke survivors. Multiple scholarly online databases and registers of published, unpublished and ongoing trials were searched, in addition articles were hand searched. MESH terms and alternatives in relation to stroke and visual conditions were used. Study selection was performed by two authors independently. Data was extracted by one author and verified by a second. The quality of the evidence was assessed using a quality appraisal tool and reporting guidelines. ***Results:*** This review included 11 studies which involved 5646 participants, the studies used a mixture of generic and vision-specific instruments. The seven instruments used by the included studies were the EQ-5D, LIFE-H, SF-36, NEI VFQ-25, VA LV VFQ-48, SRA-VFP and DLTV. ***Conclusion:*** A reduction in quality of life was reported by all studies in stroke survivors with visual impairment. Some studies used generic instruments, therefore making it difficult to extract the specific impact of the visual impairment as opposed to the other deficits caused by stroke. The majority of studies (8/11) primarily had participants with visual field loss. This skew towards visual field loss and no studies investigating the impact ocular motility prevented a comparison of the effects on quality of life due to different visual impairments caused by stroke. In order to fully understand the impact of visual impairment following stroke on quality of life, further studies need to use an appropriate vision-specific outcome measure and include all types of visual impairment which can result from a stroke.

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Appendix 7

Early development stages for a new patient reported outcome measure for stroke survivors with visual impairment.

Hepworth, L. Rowe, F. International Journal of Stroke 2016, Vol. 11 (Suppl. 4), p.51

Abstract

Introduction: To identify the most important issues for stroke survivors to aid the development of a new patient reported outcome measure (PROM). ***Method:*** A database of items was created from the questionnaires included in a recent systematic review (1277 items). Items were organised into themes resulting in 23 categories. Face validity review of these reduced the number of categories to 20 (1270 items). Lists of summarised items within each category were created after removal of duplications. A ranking exercise was completed by stroke clinicians and stroke survivors; items were ranked in their preferred order of importance. ***Results:*** 60 orthoptists and 61 stroke survivors participated in the ranking exercise. With the exception of 3 categories, stroke survivors and clinicians agreed on the top/bottom 10 rankings. All categories had a wide range of rank. All items were mapped against existing PROMs. 4 questionnaires (242 items) achieved 91.6% item coverage. Of the items covered, 54.1% were duplicated in 2 or more questionnaires. This task burden was deemed not to be a feasible or acceptable assessment. The database was used as the basis for pilot questionnaire development. The individual items (n = 1270) within the database were grouped in categories and items used during the ranking exercise. The short-listed items (n = 186) were assessed for most appropriate wording for the new questionnaire. ***Conclusion:*** A pilot questionnaire emerged, constructed of 102 items, worded in a standardised format using a 5-point Likert scale. 18 categories were organised in 2 sections – vision/eyes and functioning, with 2 separate general items using a visual analogue scale.

Using Delphi methodology in the development of a new patient reported outcome measure for stroke survivors with visual impairment

Hepworth, L.R. Rowe, F.J. Investigative Ophthalmology and Visual Science 2017, Vol. 57 (8), p.3303

Abstract

Purpose: To ascertain what items stroke survivors and stroke care professionals think are important when assessing quality of life in stroke survivors with visual impairment. ***Methods:*** Items were sourced from a systematic review of instruments relevant to visual impairment caused by stroke. The number of items were reduced and adapted following a pilot of version one of the new instrument, leading to version two (62 items). Items from version two were evaluated in a Delphi survey. Stakeholders (stroke survivors/clinicians) were invited to take part in the process. The Delphi method involved three rounds of an electronic-based questionnaire. A consensus definition of ≥70% agreement was decided *a priori.* The survey asked participants to rank importance on a 9-point scale and also categorise the items by relevance to types of visual impairment following stroke or whether items were considered not relevant. Analysis of consensus (percentage response rate), stability (mean/SD) and agreement (weighted Kappa) were conducted. ***Results:*** In total, 113 participants registered for the Delphi survey of which 47 (41.6%) completed all three rounds. Response rates to the three rounds were 78/113 (69.0%), 61/76 (81.3%) and 49/64 (76.6%) respectively. The participants included orthoptists (45.4%), occupational therapists (44.3%) and stroke survivors (10.3%). Consensus was reached on 56.5% (n=35) of items in the three round process, all for inclusion of the item. A consensus was reached for 83.8% (n=52) in the categorisation of items. The majority (82.6%) of the consensus were for relevant to 'all visual impairment following stroke'; two (3.2%) items were deemed 'not relevant'. ***Conclusions:*** If this Delphi survey had been the primary method for further development of the new instrument, a reduction of two items would have been achieved. A further 27 items would require discussion at a consensus meeting. It was identified a hub and spoke model for the questionnaire based on the categorisation of items would not be possible due to a large number of core items (n=40) and few (n=13) additional items across four spokes. Psychometrics using Rasch analysis will be assessed prior to a consensus meeting. The consensus meeting will consider all data through facilitated clinical and patient input on the important items to assess quality of life with visual impairment following stroke.

Appendix 8

Screening methods for post-stroke visual impairment: a systematic review

Hanna, K.L. Hepworth, L.R. Rowe, F. Disability and Rehabilitation 2016, 39 (25) pp.2531-2543 DOI: 10.1080/09638288.2016.1231846

Abstract

Purpose: To provide a systematic overview of the various tools available to screen for post-stroke visual impairment. ***Methods:*** A review of the literature was conducted including randomised controlled trials, controlled trials, cohort studies, observational studies, systematic reviews and retrospective medical note reviews. All languages were included and translation was obtained. Participants included adults >18 years old diagnosed with a visual impairment as a direct cause of a stroke. We searched a broad range of scholarly online resources and hand-searched articles registers of published, unpublished and on-going trials. Search terms included a variety of MESH terms and alternatives in relation to stroke and visual conditions. Study selection was performed by two authors independently. The quality of the evidence and risk of bias were assessed using the STROBE, GRACE and PRISMA statements. ***Results:*** A total of 25 articles (n¼2924) were included in this review. Articles appraised reported on tools screening solely for visual impairments or for general post-stroke disabilities inclusive of vision. The majority of identified tools screen for visual perception including visual neglect (VN), with few screening for visual acuity (VA), visual field (VF) loss or ocular motility (OM) defects. Six articles reported on nine screening tools which combined visual screening assessment alongside screening for general stroke disabilities. Of these, three included screening for VA; three screened for VF loss; three screened for OM defects and all screened for VN. Two tools screened for all visual impairments. A further 19 articles were found which reported on individual vision screening tests in stroke populations; two for VF loss; 11 for VN and six for other visual perceptual defects. Most tools cannot accurately account for those with aphasia or communicative deficits, which are common problems following a stroke. ***Conclusion:*** There is currently no standardised visual screening tool which can accurately assess all potential post-stroke visual impairments. The current tools screen for only a number of potential stroke-related impairments, which means many visual defects may be missed. The sensitivity of those which screen for all impairments is significantly lowered when patients are unable to report

symptoms. Future research is required to develop a tool capable of assessing stroke patients which encompasses all potential visual deficits and can also be easily performed by both the patients and administered by health care professionals in order to ensure all stroke survivors with visual impairment are accurately identified and managed.

Appendix 9

The treatment methods for post-stroke visual impairment: a systematic review

Hanna, K.L. Hepworth, L.R. Rowe, F.J. Brain and Behavior 2016, 7 (5) DOI: 10.1002/brb3.682

Abstract

Aim: To provide a systematic overview of interventions for stroke related visual impairments. ***Method:*** A systematic review of the literature was conducted including randomized controlled trials, controlled trials, cohort studies, observational studies, systematic reviews, and retrospective medical note reviews. All languages were included and translation obtained. This review covers adult participants (aged 18 years or over) diagnosed with a visual impairment as a direct cause of a stroke. Studies which included mixed populations were included if over 50% of the participants had a diagnosis of stroke and were discussed separately. We searched scholarly online resources and hand searched articles and registers of published, unpublished, and ongoing trials. Search terms included a variety of MESH terms and alternatives in relation to stroke and visual conditions. Article selection was performed by two authors independently. Data were extracted by one author and verified by a second. The quality of the evidence and risk of bias was assessed using appropriate tools dependent on the type of article. ***Results:*** Forty-nine articles (4142 subjects) were included in the review, including an overview of four Cochrane systematic reviews. Interventions appraised included those for visual field loss, ocular motility deficits, reduced central vision, and visual perceptual deficits. ***Conclusion:*** Further high quality randomized controlled trials are required to determine the effectiveness of interventions for treating post-stroke visual impairments. For interventions which are used in practice but do not yet have an evidence base in the literature, it is imperative that these treatments be addressed and evaluated in future studies.

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Appendix 10

Health inequalities associated with post-stroke visual impairment in the United Kingdom and Ireland: a systematic review

Hanna, K.L. Rowe, F.J. Neuro-Ophthalmology 2017, 41 (3) pp.117-136

DOI: 10.1080/01658107.2017.1279640

Abstract

The aim of this study was to report on the health inequalities facing stroke survivors with visual impairments as described in the current literature. A systemic review of the literature was conducted to investigate the potential health inequalities facing stroke survivors with subsequent visual impairments. A quality-of-evidence and risk-of-bias assessment was conducted for each of the included articles using the appropriate tool dependent on the type of article. Only four articles discussed health inequalities affecting stroke survivors with visual impairment specifically. A further 23 articles identified health inequalities after stroke, and 38 reported on health inequalities within the visually impaired UK or Irish population. Stroke survivors with visual impairment face inconsistency in eye care provision nationally, along with variability in the assessment and management of visual disorders. The subgroups identified as most at risk were females; black ethnicity; lower socioeconomic status; older age; and those with lower education attainment. The issue of inconsistent service provision for this population must be addressed in future research. Further research must be conducted in order to firmly establish whether or not stroke survivors are at risk of the aforementioned sociodemographic and economic inequalities.

Appendix 11

Published poster abstracts

Health inequalities of post-stroke visual impairment: a systematic review

Hanna K. Rowe F. International Journal of Stroke 2016, Vol. 11 (Suppl. 4), p. 51

Introduction: The aim of this review is to report on the health inequalities facing stroke survivors with visual impairments as described in the current literature. ***Method:*** A systemic review of the literature was conducted to investigate the potential health inequalities facing stroke survivors with subsequent visual impairments. We searched a vast range of resources and a quality of evidence and risk of bias assessment was conducted for each of the included articles using the appropriate tool dependent on the type of article. ***Results:*** Only two articles identified health inequalities for stroke survivors with visual impairment specifically. A further 22 articles identified health inequalities after stroke and eight reported on health inequalities within the visually impaired population. Stroke survivors with visual impairment face inconsistency in eye care provision nationally, along with variability in the assessment and management of visual disorders. The subgroups identified as most at risk were: females; black ethnicity; lower socioeconomic status; older age and those with lower education attainment. ***Discussion:*** The issue of inconsistent service provision for this population must be addressed urgently. It has only been possible to speculate whether or not stroke survivors with visual impairment are at higher risk of the additional health inequalities identified due to the lack of specific evidence. Further research must be conducted in order to establish whether or not this population are at risk of the aforementioned sociodemographic and economic inequalities.

Treatment methods for stroke related visual impairments: a systematic literature review

Hanna K, Hepworth L, Rowe F. International Journal of Stroke 2015, Vol 10 (Suppl. 5), p.47

***Introduction**:* The aim of this literature review is to provide a systematic overview of the current interventions for stroke related visual impairments. ***Methods**:* A systematic review of the literature was conducted including randomised controlled trials, controlled trials, cohort studies, observational studies and retrospective reviews. All languages were included and translation obtained. Subjects included adult participants (aged 18 years or over) diagnosed with a visual impairment as a direct cause of a stroke. Studies which included mixed populations were included if over 50% of the participants had a diagnosis of stroke and were discussed separately. We searched scholarly online resources and hand searched articles and registers of published, unpublished and ongoing trials. Search terms included a variety of MESH terms and alternatives in relation to stroke and visual conditions. Article selection was performed by two authors independently. Quality of evidence and risk of bias was assessed using the appropriate tools dependant on the type of article. ***Results**:* Thirty-eight articles (n=4563) were included in the review, including an overview of four Cochrane systematic reviews. Interventions appraised included those for visual field loss, eye movement deficits, reduced central vision and visual perceptual deficits. ***Conclusion**:* There is a strong requirement for further high-quality randomised controlled trials to determine the effectiveness of interventions for treating post-stroke visual impairments. Interventions, which are used in clinical practice but do not yet have an evidence base in the literature, should be considered and evaluated in future studies.

The impact of stroke related visual impairment on quality of life: A systematic review

Hepworth L, Rowe F. International Journal of Stroke 2015, Vol 10 (Suppl. 5), p.47

Aim: The aim of this review is to evaluate the impact of stroke related visual impairment on quality of life, measured using a patient reported outcome measure. ***Method:*** A systematic review of the literature was conducted. The review comprised of adult participants (aged 18 years or over) diagnosed with a visual impairment as a direct cause of a stroke. Studies which included mixed populations were included if over 50% of the participants had a diagnosis of stroke. We searched scholarly online resources and hand searched articles and registers of published, unpublished and ongoing trials. The search included MESH terms and alternatives in relation to stroke and visual conditions. Study selection was performed by 2 authors independently. Data was extracted by 1 author and verified by a second. The quality of the evidence was assessed using a quality appraisal tool and reporting guidelines. ***Results:*** 11 studies (5646 participants) were included in the review, which utilised both generic and vision-specific instruments. 7 different instruments were used across the studies, EQ-5D, LIFE-H, SF-36, NEI VFQ-25, VA LV VFQ-48, SRA-VFP and DLTV. ***Discussion:*** All studies reported visual impairment following stroke results in a reduced quality of life. There is an issue of extracting the specific impact of visual impairment following stroke when generic instruments are used. 8 of the 11 studies focused on visual field loss following stroke. Further research is required to investigate the impact on quality of life from all facets of visual impairment following stroke using appropriate vision-specific outcome measures.

Views of stroke survivors on impact of visual impairment

Rowe F.J. Investigative Ophthalmology and Visual Science 2015, Vol 56 (7), p.498

Purpose: Visual impairment is considered to add impact to daily life over that already incurred by general problems due to the stroke. In this study we sought to ask stroke survivors directly about their experiences of visual impairment to determine impact on daily life. ***Methods:*** We recruited stroke survivors with visual impairment who were more than one year post stroke onset. Biographical narrative interviews commenced with a pre-constructed single narrative question followed with additional narratives relating to the sequence of topics raised and non-narrative questions to explore topics further. Interviews were audio-recorded and transcribed verbatim. A thematic approach to analysis of the qualitative data was adopted. Transcripts were systematically coded using NVivo10 qualitative software. ***Results:*** We interviewed 35 stroke survivors across the UK: 16 females and 19 males aged 20 to 75 years at stroke onset. A number of themes emerged. Where visual problems existed, they were often attributed to other causes such as migraine. Visual problems included visual field loss, double vision, reading, glare/photophobia, blurred vision and perceptual problems. Impact of visual problems typically included loss in confidence, increased collisions/accidents, fear of crowded places and fear of falling. These individuals made many adaptations to compensate for their visual problem(s): magnifiers, large print, taking extra care/caution, de-cluttering their environment, increased lighting and use of a white stick. Many individuals did not receive early vision assessment or treatment for their visual problems. ***Conclusions:*** There is a consistent lack of post-stroke support and provision of information about visual problems. Stroke survivors and their carers felt there was a need for improvement of education to promote knowledge and increased awareness of post-stroke visual impairment.

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Ms Janet Rockliffe

Stroke service user

Mr Brin Helliwell

Stroke service user