Care provision and unmet need for post-stroke vision problems

What are post-stroke vision problems?
Following stroke, people may have visual symptoms and visual conditions (problems seeing and difficulties with their eyes). These vision problems add to the general problems caused by stroke. Visual problems can affect many aspects of daily life, such as ability to walk about without knocking into objects, prepare food, drive, read and can reduce involvement in social activities. Vision conditions can affect our vision as we look straight ahead – our centre vision – or our outer vision to the sides. They may include a variety of eye movement problems and the way in which we see things can also change.

There is a problem with how we care for people with vision problems after stroke. Vision testing is not routinely done for these people. There are many differences across the UK for getting access to eye care services for specialist testing and treatment.

Why was some research needed?
In 2013, the Stroke Association and Thomas Pocklington Trust identified a number of key questions relating to the care of people with visual problems after stroke and to find out whether stroke survivors, who have visual conditions, still have visual problems that have not been addressed (unmet need).

What did we do?
We reviewed what work has been published in the past. We surveyed UK-based stroke teams and eye teams, we talked to stroke survivors and we talked to existing service providers for stroke and vision care.

What did we find?
How much unmet need exists?
Stroke survivors often still had problems that had not been addressed in relation to their vision. Few clinicians used a standard plan of care for stroke survivors with vision problems. Many referrals for stroke survivors with visual problems were inaccurate. Stroke survivors, carers and clinicians reported the need for better information about vision problems.

Is there a clear pathway for vision care in stroke survivors?
The British and Irish Orthoptic Society have produced a clear pathway for vision after stroke. This is freely available, but few health professionals seem to use it. Some departments use their own local pathway.
What are the variations in vision care - how might they be addressed?

There were large differences across services as to who takes responsibility for vision screening (checking whether there are vision problems or not). Our interviews showed a preference for vision screening to be done by orthoptists. If this was not possible, then the preference was for training for stroke teams to be given by orthoptists. Clinicians and stroke survivors said they were not given information leaflets about vision despite these being freely available from organisations such as the Stroke Association and RNIB. A recommendation from stroke survivors, their carers and clinicians was for improvement in education to increase knowledge and greater awareness of post-stroke vision problems.

What is best practice in vision care for stroke survivors?

A best practice statement and recommendations for vision care for stroke survivors is available in Scotland. From our interview results across the UK, we identified a number of recommendations to promote best practice across all stroke units. These included formal orthoptic care, flexible and timely appointments, formal stroke team training, full support from stroke doctors, lay summaries, open communication between eye care and stroke teams, visual information leaflets, use of approved referral forms and use of a vision care pathway. A number of issues were suggested that could cause vision services to fail. These included a lack of funding, lack of orthoptic cover, staff retraining, lack of stroke doctor support and incorrect information about visual problems.

What are the key issues?

Across the UK there is inequality in care provision for stroke survivors with visual problems. Stroke survivors continue to have unmet needs with their visual problems. There are differences for:

- how vision screening happens,
- which vision tests are used,
- how stroke survivors with visual problems are referred to eye care services,
- how the visual problems are managed, and
- what vision information is given to stroke survivors and their carers.

Existing screening methods, vision tests and care pathways (whether locally or nationally agreed) should be adopted and applied widely. Education is needed at many levels to increase awareness and knowledge of the visual problems that may occur after stroke and with information leaflets about vision given as early as is appropriate for the individual but always before discharge.

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