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The project team

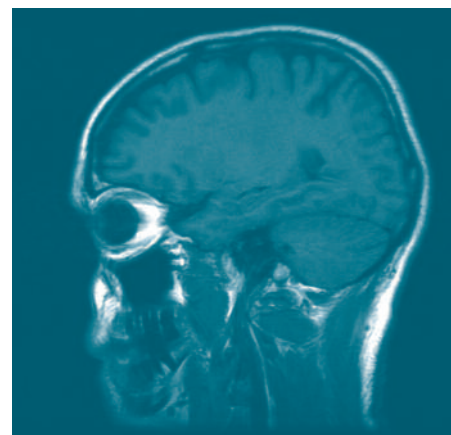
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Introduction

This study explored current approaches to communicating information to stroke survivors and their relatives. The project's aim was to gain better understanding of information provision about stroke from health professionals. It explored the perspectives of stroke survivors, their carers and professionals. The study aimed to explore, through qualitative interviews, how information is provided, what works well in information giving, what the barriers to good information provision are and how these arise.

The study helped develop an information toolkit for service providers, stroke survivors and relatives to engage in effective person-centred communication. The study is based on interviews conducted with health professionals in acute, community and primary care settings in East Kent and with a small sample of stroke survivors and carers.

We interviewed 19 stroke survivors, 6 relatives and 23 health professionals (11 individually and 12 in 2 focus groups) involved in their care and support.

Research questions

The study addressed the following:

- What perceptions do health professionals and service providers have of the information needs of patients and what strategies do they employ to meet these?
- What type of information do health professionals in acute, community and rehabilitation services have on stroke risks and how do they use it to advise on life style adjustments?
- What information needs do stroke survivors and their relatives have about risk factors and how to minimise them?
- What perceptions do stroke survivors and their relatives have about risk factors in stroke?
- How have stroke survivors used information about stroke in their daily lives?
- What are the factors that influence information exchange on secondary prevention, risk and self management of stroke?

Key findings

Communication of information: professional, stroke survivors and relatives

- Health professionals working in different parts of the care system had varied insights into the information needs of stroke survivors.
- Stroke survivors had changing information needs at different stages of their recovery; therefore timing of information for the different stages is crucial in ensuring that stroke survivors understand information fully and remember it.
- Immediately following a stroke, survivors and relatives can find it difficult to absorb information.
- Initially stroke survivors and relatives are most concerned about what has happened and their chances of survival.
- Memory and communication problems can contribute to difficulties in receiving, understanding and retaining information.
- Members of the stroke team all had different information to give and there is not always overall coordination of information to ensure comprehensiveness.
- Health professionals in acute and community services were aware that there can be gaps in information giving. They also were not always aware of what information others had given.
- Health professionals recognised survivors' needs for emotional support as part of the process of information giving.
- There can be an information overload when stroke survivors are discharged from hospital.

Support and rehabilitation in the community

- GPs saw their role primarily in terms of providing information on secondary prevention, for example, on cholesterol levels or blood pressure, rather than broader information on psychological and emotional aspects of rehabilitation.
- The community rehabilitation team felt there was sometimes a gap in communication between themselves and the hospital. This could result in a delay in care for the stroke survivors and their families.
- The stroke specialist nurse provided a post discharge follow-up phone call as she felt that most problems did not emerge until the survivor was back at home.
- The stroke family support worker saw her job as signposting people to support agencies, tailoring the information to their needs and lending a listening ear.
- Accurate information enables stroke survivors to make informed decisions about treatment and treatment options.
- The provision of information can aid a positive attitude to recovery.

- One stroke consultant felt that information given to stroke survivors and their families which was tailored to their individual needs enabled them to make informed choices within the context of their lives.

Stroke survivors and carers

- Stroke survivors stressed that appropriate and timely information helped them to understand what had happened, how they could reduce the chance it could happen again and how they could make the best use of support and services. Information that survivors and their families wanted depended on their particular circumstances, but also where they were in the recovery process.
- Stroke survivors and relatives did not always want to 'hear' information which did not fit with their hopes and aspirations.
- Stroke survivors and families often did not know anything about stroke and information giving therefore needed to start from a very basic platform.
- Stroke survivors and their families did not always know what questions to ask. This was particularly the case immediately after the stroke when they were likely to experience difficulty both in articulating questions and in understanding answers. Stroke survivors and relatives wanted opportunities in hospital and after discharge to ask questions and gain information.
- Information needs are likely to change over time.

Preferences in information communication

- Some stroke survivors may be very proactive in their information seeking, others may not have the capabilities or may not wish to do so. Information about stroke and recovery needs to be offered to survivors and relatives – the onus should not be on them to find out.
- Stroke survivors and their relatives found it helpful when a specific time for information giving with the patient and their relatives was 'booked' or set aside. On occasion, information was given in a hurry, particularly in hospital. Stroke survivors found this unhelpful and found it more difficult to ask questions when they perceived that health professionals were rushed.
- For stroke survivors and their relatives, information provision is only one aspect of the stroke experience, but it is pivotal to building a successful dialogue between health professionals and stroke survivor over the longer term.
- Stroke survivors noted and appreciated when health professionals used varied tools and methods to explain information about stroke, including the use of scans, drawings and charts.

TIA or minor strokes

- Survivors and relatives considered there was a gap in the information provided by health professionals and contained in the stroke information leaflets.

- Hospital admissions for TIA or minor stroke were brief and, because the survivors often had no physical needs, they could be overlooked by busy staff and could miss opportunities to access information and ask questions.
- In the community, this group was usually not eligible for services from the rehabilitation team and did not receive sufficient information and reassurance between out patient appointments.

Driving after stroke

- While most stroke survivors thought that there were clear instructions in the written information guidance, for example those issued by the Stroke Association, some stroke survivors found the details vague.
- Losing the right to drive not only created major practical problems but was also a threat to independence and a sense of being a competent adult. Most survivors and their relatives felt that they were well supported by health professionals and given clear advice. However, a small number of participants chose to ignore the advice given about driving.
- Some stroke survivors lost confidence about driving.
- Professionals involved in stroke care felt able to give general information about post-stroke driving but referred the survivor back to the consultant or GP for more specialised advice.

Secondary prevention after stroke

- Most stroke survivors were frightened of having a second stroke and were concerned to prevent it happening again.
- Survivors and their relatives wanted information about aspects of their lives they could take control of to minimise the risks of another stroke.
- Stroke survivors and carers felt the advice they were given was not specific enough in the context of their everyday lives, for example, how strenuously they could exercise at the gym.
- Survivors and relatives obtained their information from a variety of sources, including, information leaflets, the internet, newspapers but face-to-face communication with professional was an important and valued source of authoritative advice.

Information on medication

- Stroke survivors and carers indicated that they often had gaps in their knowledge of the medication they took. This included their role in reducing the risk of further strokes, in managing underlying clinical conditions and information about the potential and actual side effects. Knowing about these was important to stroke survivors particularly when medication was prescribed and had to be taken long-term.

- Stroke survivors and their relatives may find it difficult to recall information on medication because they have not had to deal with it during the hospital stay. They felt that information on medication needed to be repeated and written down in detail on discharge.
- Stroke survivors and their relatives wanted opportunities to discuss, understand and gain reassurance on the often complex medication regimes early and discuss side effects. They felt that sometimes there was a lack in the continuity of care between acute, intermediate and primary services in relation to medication.
- Individuals who had TIAs and minor strokes in particular did not receive full information on medication and welcomed greater opportunities to discuss their medications and its possible side effects.

Recommendations

The responses of stroke survivors and carers indicate that they receive a substantial amount of information through various channels, in different ways, and that there are examples of good practice. There remain gaps in the information provision, particularly with regard to information about the personal circumstances and individual information needs, which need addressing.

Overall we would recommend

- That the stroke services in East Kent develop an information provision strategy, which is an integrated part the overall stroke service development across the acute and community and primary care services.
- This strategy should aim for a person-centred approach, which can be responsive to the changing information needs of stroke survivors and their families. It should be based on a personalised approach to information provision, which is tailored to the individual circumstances of stroke survivors.
- The strategy should integrate and expand on the successful local elements of information provision, but also should look outside the area for evidence of good practice.
- The development of the strategy should involve the health and social care and voluntary sector stakeholders, as well as patient groups. Stroke survivors, carers and health professionals should be closely involved in its design and use their experiences and expertise in reviewing it. It should be disseminated widely and proactively across the service area.
- The information strategy should not only provide written materials, but also examples of continuous communication between health professionals and stroke survivors, developing and cascading examples of good practice, training and education, and the use of third party information provision (for example, the use of internet websites etc).

We would also recommend

- During the hospital stay, the coordination of information provision could be further streamlined, so that all patients and carers are prepared appropriately for discharge and are reassured about their continuity of care when they return home. This is particularly important in the context of shorter hospital stays, which limits the opportunities for information exchange between health professionals in hospital and patient/carer.
- Patients who had a TIA or minor stroke often do not have the opportunity to discuss their strokes and receive advice and information. Particular attention should be paid to improving information access and continuous support for this group of patients.
- Stroke survivors and carers need the space at different intervals in the recovery process to address their changing information needs. Primary care should assume a greater role in proactively discussing stroke information particularly at later stages of the recovery process.
- We found a number of gaps in the provision of information about medication, particularly on discharge from hospital and in the community. Information about the medication taken needs to be provided in writing and in a way stroke survivors and their families and carers can understand. Developing an effective and innovative solution to this could involve pharmacy services in hospital and in the community.
- Greater emphasis should be placed on detailed and continued advice and information on life style, not only to help minimise the risk of further stroke generally, but also to increase the feeling of control stroke survivors have over their lives. It should include, for example, discussions of relevant aspects of every-day life such as diet, physical exercise and stress, including a discussion of what the stroke survivor already does and what she/he would like to achieve.

Centre for Health Services Studies

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The Centre is directed by Professor Andy Alaszewski and draws together a wide range of research and disciplinary expertise, including health and social policy, medical sociology, public health and epidemiology, geriatric medicine, primary care, physiotherapy, statistical and information analysis. CHSS supports research in the NHS in Kent, Surrey and Sussex and has a programme of national and international health services research. While CHSS undertakes research in a wide range of health and health care topics, its main research programmes comprise-

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