

REVIEW

Inadequacies in the provision of information to stroke patients and their families

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Introduction

It was disquieting to find during an audit of our stroke service that, despite general satisfaction with their care, 40% of patients and carers were dissatisfied with the information that they had received during their inpatient stay. This prompted us to review current practice, seek the views of patients and carers, examine ways of improving this aspect of care, and review the literature about education and information provision following stroke. The literature demonstrates considerable gaps in current knowledge about the most effective and acceptable ways of providing stroke patients and carers with the information that they require.

Identifying the information needs of stroke patients and informal carers

The World Health Organisation advises that “patients have a right to be given factual, supportable, understandable and appropriate information” about their condition. Patients who feel poorly informed are less satisfied with their care, are less likely to comply with medical advice and have poorer outcomes [1–3].

The National Sentinel Audit for Stroke has highlighted communication as an issue which is poorly addressed [4]. Studies have repeatedly found that stroke patients and their families feel inadequately informed about all aspects of stroke disease and available support [5–8]. In particular, their need for information about the emotional consequences of stroke is not met [6, 8, 9]. The level of dissatisfaction with information given found in our audit was similar to that of previously published work [10].

Stroke patients and their carers wish to be informed about all aspects of care and be involved in decisions but have difficulty obtaining the information they require [7, 11]: staff are perceived as too busy or not available, people feel reluctant to ask questions and the explanations given are often too complicated or do not address personal concerns [10, 12].

Lack of information, leading to misconceptions, anxiety and fear, is believed to be a contributory factor to poor health status and emotional problems [13], both of which are common among stroke survivors and their carers [14]. Research evaluating information services in conditions other than stroke suggests that individualized information can lead to better quality of life [15–17].

Current provision of information about stroke

Despite widespread evidence of the need to improve information-giving for stroke patients and carers, relatively few evaluations of the content and methods of delivery have been undertaken. Individual units have tended to develop their own information sheets, supported by literature from voluntary agencies, the acceptability and readability of which has often not been tested. Neither is it apparent that the available information addresses those issues which are important to patients and carers [18, 19]. In stroke, as in other areas of health care, information is often based upon what health professionals think patients and carers want to know [20–23]. The approach has predominantly been passive provision of information rather than involving patients and carers in active learning and problem solving.

Computers, tapes, videos and other technologies have not been evaluated.

The UK National Clinical Guidelines for Stroke recognize the importance of providing information and have two recommendations in this area [11]:

1. The needs of the family to be given information, to be involved in taking decisions and making plans, and to be given support, must be considered from the outset.
2. Information should be given to families on the nature of stroke and its manifestations, and on relevant local and national services.

However, no advice is given as to how this is best achieved.

Information needs change over time. A study from New Zealand found that patients and carers continued to have unanswered questions for a long time after stroke, although the areas of concern changed [12]. At 2 weeks after stroke the most frequently asked questions were about the causes of stroke (50%), the nature of stroke (32%), the association of stress and stroke (23%), and recovery (22%). At 6 months, questions related to risk of recurrence (19%), the causes of stroke (15%), the nature of stroke (14%) and medication (12%). Two years after stroke, poor memory or concentration (32%), risk of recurrence (19%) and balance problems (19%) were the main issues of concern, but 14% still had unanswered questions on the causes of stroke.

Emphasis on the provision of education and information is one of the features which is believed to distinguish stroke-unit care from conventional care, although the evidence to support this view is not rigorous [24]. One randomized trial ($n=315$) has compared the knowledge of patients cared for on a stroke unit with that of patients admitted to general medical wards [25]. Stroke-unit patients received more information about stroke and were more satisfied with the quality of information and communication, but were not more knowledgeable about stroke. At 12 months, patients who had been cared for in the stroke unit were more likely to report that they were aware of the causes of their stroke and were aware of the risk of further stroke, although the study did not identify whether or not these beliefs were actually correct.

Randomized controlled trials of written information about stroke

Trials evaluating the effectiveness of written information are limited and compromised by inadequate statistical power. One study ($n=92$) randomized patients and relatives 1–2 weeks after admission to receive a general 12-page booklet, addressing stroke aetiology, risk factors, treatment, recovery, community services and details of benefits and allowances, or standard care [26]. Participants were interviewed 1 week later about their

knowledge of stroke. Patients who received the booklet knew more about the aetiology of stroke and risk factors but no differences were found in awareness of prognosis or availability of benefits. Despite having been given the booklet, 35% of patients and 38% of relatives still stated that they had received no information. It is likely that a number of stroke units, recognizing the information needs of patients and carers, have produced similar booklets giving general information about stroke which appear to be of limited efficacy.

A further small randomized study ($n=36$) evaluated personalized booklets which were distributed at discharge and contained individualized information about symptoms and rehabilitation aims, advice on activities of daily living and exercises, and local and national contacts [27]. No differences were found in basic or extended activities of daily living, knowledge of stroke or satisfaction. Only 50% of participants felt that the booklet was useful. One of the reasons given by those who felt the booklet was not useful was that the patient's condition had changed since receiving the booklet so it was no longer felt to be relevant, indicating the need for continued assessment and revision of information. The carers of patients who received the booklet scored better on the mental health component of the short form 36.

As part of a pilot study ($n=93$) for a larger ongoing evaluation of a Stroke Association family support organizer, patients were randomized to receive an information pack 1 month post-stroke or at discharge from hospital (whichever was sooner), or to receive conventional care [28]. The pack contained eight Stroke Association leaflets, information about local services and local and national contact names. No important differences were found in knowledge, satisfaction or disability.

Studies of education programmes for stroke patients and carers

An American randomized controlled trial evaluated an education programme for carers which consisted of two 1-h classes starting 3 weeks post-admission [29]. The value of counselling for carers (7 h with a trained counsellor during admission and post-discharge) in addition to the education programme was also assessed. The trial compared patient and carer outcomes following: (i) an education programme for carers covering the basic principles of stroke care ($n=64$); (ii) counselling sessions for carers plus the education programme ($n=63$); and (iii) conventional care ($n=61$). At 6 months and 1 year post-stroke, both interventions significantly improved caregiver knowledge of stroke and improved some aspects of family function. Counselling was consistently more effective than education alone, and resulted in better patient adjustment at 1 year.

In response to the findings of our local stroke-service audit, we established a multi-disciplinary stroke-education programme comprising a rolling programme of seven

1-h small group sessions, six of which were provided following discharge at our day hospital. The programme aimed to improve patient and carer knowledge about stroke and local services. Each programme had a facilitator, and informal group discussions followed each session. Participants were encouraged to seek advice either within the group or individually.

Two hundred and four patients and 176 informal carers participated in a randomized controlled trial to evaluate the service [30]. The stroke-education programme did increase knowledge about stroke and increased satisfaction with services but was not associated with improved health status. Indeed, the social functioning of carers randomized to the stroke-education programme was reduced. Attendance was disappointingly low (45% of surviving patients and 21% of carers).

Studies of the provision of information by a stroke specialist nurse or stroke family support organizer

A single-centre study evaluated a stroke nurse-specialist service which provided advice, information and support to patients and carers in their own home in the 12 months after discharge [31, 32]. The study ($n=240$) found no differences in outcomes between intervention and control groups. Patient and carer knowledge of stroke disease and available services was not assessed. Subgroup analysis suggested that patients with mild disability who were visited by the specialist nursing service were more involved in social activities at 3 and 6 months post-stroke than control subjects.

Although the results of the randomized controlled trial were disappointing, a qualitative substudy found that patients and carers visited by the specialist nurse felt that they had received personalized support, practical help and information, while the control group felt that they lacked personally relevant information which would have helped them practically and emotionally [32].

The use of complementary research methods to evaluate this intervention did identify differences in patient and carer experience between those who received the new service (which included provision of information as one of its components) and those who received conventional care. Randomized controlled trials by themselves may fail to detect important benefits from complex interventions because of limitations in currently available outcome measures or because trials have lacked statistical power. Thus, it is of concern that services may be wrongly deemed to be ineffective because of poor study design.

In the UK, the Stroke Association has established a stroke family support service. The service aims to offer patients and their families advice, information and emotional support for up to 12 months following stroke. Family support organizers come from a range of

clinical and social care backgrounds, and training is provided by the Stroke Association. The family support service is able to visit patients and their families at home or in hospital, respond to telephone enquiries, and provide leaflets and contact details of local stroke groups and support networks.

An observational study involving 16 stroke family support organizers confirmed that provision of information was a major component of their role. Twenty-two percent of their activities related to provision of information about benefits, medication, health, tasks and support, and a further 45% related to conversations with patients and their families about issues relevant to stroke [33].

There are two published randomized controlled trials of stroke family support organizers. Both have evaluated the service provided by a single individual. A further two trials are under way.

In the Edinburgh study, patients ($n=417$) and carers ($n=246$) who saw the stroke family support organizer felt better informed about rehabilitation and recovery after stroke but not about the causes and nature of stroke [34]. While patients and carers who saw the family support organizer were more satisfied with aspects of their care than those in the control group, no differences were seen in functional abilities, mood or adjustment of either patients or carers.

A more recent study from Oxford (323 patients, 267 carers) found that carers who received stroke family support were more active, had better psycho-social outcomes and were more satisfied with their understanding of stroke than the control group. No differences were found in patient outcomes including their knowledge about stroke [35].

Other studies have evaluated services which aim to reduce psycho-social difficulties after stroke. Although these services provided counselling and social support, they have not been included in this review as provision of information and education was not one of their specified objectives [36, 37]. The results of a systematic review of information provision for stroke patients and their carers are awaited [38].

Conclusions

Observational surveys have clearly and consistently demonstrated that many stroke patients and their families express both a lack of understanding and a desire for further knowledge about the causes and consequences of stroke, secondary preventative measures and the availability of both statutory and informal support agencies. Although studies are limited, available evidence suggests that the methods of providing information to stroke patients and carers currently used in clinical practice are ineffective and need to be improved.

Stroke services should aim to provide information that is timely and in an appropriate format. In order to

Table 1. Medical Research Council framework for trials of complex interventions

Pre-clinical	Theory	Explore relevant theory to ensure best choice of intervention and hypothesis and to predict major confounders and strategic design issues
Phase I	Modelling	Identify the components of the intervention, and the underlying mechanisms by which they will influence outcomes to provide evidence that you can predict how they relate to and interact with each other
Phase II	Exploratory trial	Describe the constant variable components of a replicable intervention <i>and</i> a feasible protocol for comparing the intervention to an appropriate alternative
Phase III	Definitive randomized controlled trial	Compare a fully-defined intervention to an appropriate alternative using a protocol that is theoretically defensible, reproducible and adequately controlled, in a study with appropriate statistical power
Phase IV	Long-term implementation	Determine whether others can reliably replicate your intervention and results in uncontrolled settings over the long term

improve stroke information-giving, a better understanding of the impact of stroke from the patient's and carer's perspective is required. Information predominantly derived from the professional viewpoint is less likely to be effective [32, 39, 40].

To improve the quality of care available to stroke patients and their families, we need to be clear about the information needs of patients and carers, and to recognize that these may differ. Information may need to be repeated and reinforced on a number of occasions. We also need to know the effectiveness of different approaches to provision of information and the value of different media. Perhaps we should not only be providing information, but also teaching patients and carers problem-solving skills.

Further development of information and education strategies will require the underpinning of a sound theoretical basis to aid their design. Future research should follow the framework suggested by the Medical Research Council (Table 1) [41].

Improvement in trial design is also needed [42]. Future studies should have a secure randomization procedure, blinded outcome assessment and relatively complete follow-up, adequate statistical power, and be analysed on an intention-to-treat basis. The outcome measures used should be validated and appropriate to the intervention. A clear description of the intervention is essential.

It is important that we are certain that our information services for stroke patients and their families are effective and successfully address their needs. We need to avoid providing information in ways that may be ineffective, despite our best efforts and intentions.

Key points

- Patients and carers feel poorly informed about all aspects of stroke disease and available support.
- Further research is needed to evaluate the most acceptable and effective ways of providing information.

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