



RESEARCH

INFORMATION

Improving communication and shared decision making in major stroke



AIMS

To understand the progress and abilities of patients admitted with major stroke to aid communication of prognosis.

To understand the experiences and decision-making approaches of patients admitted with major stroke and their families

To find ways to improve communication of information between doctors and patients/families in the context of a major stroke

For this project, we defined major stroke as those patients who were significantly physically disabled and had at least two abilities affected by the stroke (that is, their ability to walk, to talk, to eat normally or to be continent)



KEY FINDINGS

- Patients with major stroke varied with respect to their specific abilities to talk, to walk, to eat normally, to be able to live at home and to live without major anxiety or depression. Even if they were all physically disabled (according to widely used stroke outcome scales), they reported variability in their quality of life.
- Patients were looking for hope that they would get better in the early period after major stroke. However, six months later, they wished they had been given information to have helped them prepare for the impact of stroke. Psychological support seemed important.
- Family members who made decisions for the patient did so having considered how the patient's health was like before the stroke and if the patient had expressed any wishes about treatments or living with disability. They looked for information from doctors for various purposes (e.g. to justify a decision they had already made, to arrive at a treatment decision or to look for hope that the patient would improve). Different individuals wished information presented in different formats (e.g. pictures, words, ratios)
- We have developed mathematical models to predict patient abilities after major stroke. These may be used to provide patients and families with information they require on the likely impact of major stroke.



WHAT DID THE STUDY INVOLVE?

This was a mixed methods study which combined a variety of methods.

The study involved the recruitment of 403 patients with major stroke and the observation of their progress over six months. Patients and/or their families were asked about the patients' abilities (e.g. to walk, talk, eat normally) and answered questions on how they perceived their quality of life.

From these 403 patients, we interviewed 15 patients and 24 family members in hospital in the early period after stroke and six months later to explore their experiences, needs (information and psychological support) and how they made treatment decisions. This gave us insight into how doctors may be able to support patients and families better.

Using data from large trials (from over 13000 patients), we developed mathematical models that could predict specific abilities after major stroke that may be used to provide information to patients and their families. We tested how these models worked by using data we collected from the 403 patients we recruited.



WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

Patients varied with respect to their specific abilities and quality of life. This means that using terms such as 'dependent' or 'disabled' when communicating prognosis after major stroke to patients and families is not accurate and does not give the full picture of the patient's abilities. Therefore, communicating specific abilities may be more appropriate. From our models predicting specific abilities after major stroke, we have shown that some of these abilities (e.g. to talk, to walk, to eat normally, to live at home) can be predicted and therefore, used to provide patients and their families with information on the impact of major stroke. However, we need to further evaluate these models before they can be used to guide individual patient management. Our results provide evidence for changing the way doctors currently communicate with patients and families.

We know from previous research that patients wish to be involved in making treatment decisions. However, our results show that in the early period after major stroke, patients are looking for hope; they are distressed and may not engage with information. However, we also found out that patients retrospectively wished they had been given information early on. So, this means that doctors need to provide tailored information to patients at an appropriate time and also find a way of providing a record of this information that patients may revisit when they feel able to do so. Our results also provide evidence that psychological support is important for patients who have suffered from a major stroke.

We also know from previous research that family members wish to be involved in making decisions for the patient, and most patients wish their family members to be involved. This study provides more insight into this by revealing that different family members wish different information depending on the patient's state of health and expressed wishes prior to the stroke. This difference in patients' state of health also determined the family members' experiences, needs and treatment decision-making approaches. Therefore, our results allow doctors to prepare with necessary information before approaching family members to discuss patient diagnosis and prognosis.



WHAT IMPACT COULD THE FINDINGS HAVE?

Patients

We understand the needs and experiences of patients with major stroke better. With this information, we can develop a method of communication that may be more appropriate, useful and tailored to their needs

We also better understand how family members make decisions on behalf of the patient and their accompanying experiences and needs. This information may allow doctors to tailor their communication of information better

Practice

Our results provide evidence for a change in the way doctors currently communicate information. For example, to communicate prognosis based on specific abilities (e.g. the ability of patients to walk, to talk etc) rather than using terms such as 'dependent' or 'disabled'. Also, to provide tailored, relevant information that focuses on patient needs and wishes, thereby promoting patient centred care

Policy

Patient-centred shared decision-making supported by effective patient orientated information about treatment options and outcomes

Patient and family support in the early period after stroke, and ongoing psychological support in the community

Development of a communication tool to aid tailored communication

Staff training on communication in the context of a major stroke



HOW WILL THE OUTCOMES BE DISSEMINATED?

We have published a leading opinion and a podcast in the International Journal of Stroke. Results from our patient interviews have been published in PLOS one. Three further papers are currently under consideration with journals.

We have also presented findings at several national and international conferences, including the European Stroke Conference and the UK Stroke Forum.

Our next piece of research will be to develop and refine a communication tool for tailoring communication in the context of a major stroke. We have received funding from the Lothian Health Foundation to start this work.



CONCLUSION

By using a mixed methods approach, we have found that tailored information and psychological support for patients and their family members in the context of a major stroke is important in facilitating shared decision-making. A communication tool providing tailored, consistent information in different formats to suit different individuals is a first step in facilitating this process. Future research is needed in using mathematical models to guide individual patient management and further refining and evaluating this communication tool in achieving outcomes in-keeping with patient wishes.



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