

FOCUS ON RESEARCH

APPROPRIATE PATIENT-CENTRED OUTCOMES FOR YOUNG ADULTS POST-STROKE AND THEIR FAMILIES

Researchers

Maggie Lawrence, Dr Sue Kinn, Professor Val Fleming

Aim

The aim of this study was to:

1. Identify what patient-centred outcomes measures are used in stroke services
2. Describe the issues that are important to young adults who have had a stroke and their families
3. Determine if these issues change over time
4. Determine whether current service provision meets the needs of young adults and their families

Project Outline/Methodology

In order to address the four aims of this study three different research methods were used. A systematic review of the patient-centred stroke literature was conducted to identify patient-centred outcomes measures used currently in stroke care. An innovative methodology was used which allowed the inclusion of a broad range of evidence. Also, this method permitted a thematic analysis of the review papers.

A qualitative interview study was conducted to enable description of the issues identified as important by the participants. Ten young adults and eleven of their family members took part in interviews over a period of up to two years.

The final aim was addressed by means of a questionnaire survey posted out to members of the Scottish Stroke Nurse Forum.

Key Results

Systematic Review: Two patient-centred stroke outcomes measures were identified: the Stroke Impact Scale and the Subjective Index of Physical and Social Outcome. Three thematic concepts were identified: meaningfulness and relevance, quality and communication.

Qualitative study: Shock due to the sudden onset of stroke and fear of recurrence are two factors which impact on the lives of young adults. In addition they are concerned about their ability to return to 'normal'. How they are perceived and treated by other people is important to them as are driving and returning to work. For family members there is a sense that life has changed forever. However, as time progresses other major events occur and the

focus of attention shifts to another member of the family; life moves on.

The **questionnaire survey** revealed that charities such as Chest Heart Stroke Scotland are the largest providers of community-based support services, including services for young adults and their families.

Conclusions

The findings suggest that stroke services provision is moving towards a patient-centred approach to care. However, a family-centred approach should be considered as stroke impacts on the whole family. The study also highlights the need to provide stroke clinicians with the skills which will enable them to actively involve adults with aphasia (communication difficulties) and their families in setting rehabilitation goals.

What does this study add to the field?

The study identified a need for:

- family-centred rehabilitation
- patients with communication impairments are often excluded from active involvement in planning rehabilitation goals

Implications for Practice or Policy

- Utilise outcome measures which support patient-centred practice.
- Provide family-centred assessment/rehabilitation.
- Aim for a return to independence of an activity in the pre-stroke form, where possible.
- Equip stroke healthcare professionals with the communication skills they require in order to be able to maximise the involvement of patients with aphasia in rehabilitation goal planning.

Where to next?

Plans include maintaining the dialogue instigated with researchers developing systematic review methods. A proposal is being developed for a study which will investigate the impact of stroke on younger family members. Dialogue will continue with international colleagues regarding the development of qualitative methods.

Further details from:

M. Lawrence, NMAHP Research Unit,
Glasgow Caledonian University, G4 0BA
Email: margaret.lawrence@gcal.ac.uk

