possible effects of unrealistic expectations of recovery after stroke

Peter Hobson, Sian Ramessur and Josie Wray report on a study to determine if an unrealistic patient expectation of recovery is associated with depression

Until recently, the evaluation of medical interventions relied upon measures of morbidity and mortality and clinical tests. However, there is now greater recognition of patients' subjective points of view in the evaluation of their care (DHSS 1983). Patients and their carers are regarded as vital partners in the decision making process and their role should not be underestimated. The quality of rehabilitation care, ultimately the patient's health-related quality of life, also depends upon this process of partnership with health professionals.

Most research which has sought the views of consumers, has tended to focus upon patient satisfaction with the services provided in hospital and when they are discharged. Studies have shown that patient satisfaction is associated with the differences in care received and better provision of information (Pascoe 1983, Cleary and McNeil 1988). However, satisfaction with services is not necessarily associated with better health functioning (Pound et al 1999). More recently patient expectations and outcomes of their treatment have been investigated in a number of conditions (Borkan and Quirk 1992, Brown et al 1995, Scolte op Reimer 1996). In one study the expectations of older hip fracture patients making a full recovery when treated in a specialist rehabilitation setting were significantly associated with better outcomes in physical recovery (Borkan and Quirk 1992).

Stroke is a common cause of mortality in England and Wales and is a significant predictor of significant long-term physical disability. A number of studies have investigated patient satisfaction with stroke services and these have found that greater satisfaction is associated with the provision of better services, patient information and the patient's personal characteristics (Pound et al 1994, Wellwood et al 1995, Scolte op Reimer et al 1996, Bisset et al 1998, Clarke and Smith 1998, Rao 1998, Pound et al 1999).

Depression after stroke is also common and is considered to be a major predictor of poor physical rehabilitation and a prognostic indicator of long-term handicap due to poor psychosocial functioning (Young and Forster 1992, Astrom et al 1993). These patients are also often found to be more dissatisfied with services (Scolte op Reimer et al 1996). Unfulfilled expectations, because of either unrealistic optimism or undue pessimism about recovery, may increase handicap after stroke. The relationship with handicap is therefore an important determinant of the overall stroke rehabilitation process.

This study aims to explore whether patient expectation of recovery post stroke reflects that of the health professional, and if expectations are not met, whether this results in depressive symptoms.

methods

Sixty-one stroke patients aged 60 years or more (all of whom had a primary diagnosis of computerised tomography (CT) scan confirmed first, or recurrent ischaemic stroke) were recruited into the study. Patients were excluded from the study if they had significant pre-existing dementia (based on clinical history and an abbreviated mental test (AMT) score of less than six), severe aphasia (scores of less than three on the Boston Diagnostic Aphasia Examination (Goodglass and Kaplan 1983)), severe life threatening co-morbidity or were unable to give consent to participate in the study. Fifteen patients were excluded from the study of which nine were considered to be suffering from severe cognitive impairments and six had severe speech and language difficulties.

Since there is no standardised specific patient expectation measure available for stroke patients or health professionals, a scale was developed to allow patients subjectively to assess their expectation of physical recovery after stroke (Box 1). The questionnaire covered the areas of mobility, speech and language functioning and self-care. Patients subjectively rated their own overall expectation of recovery as either dependent or independent functioning. Health professionals also employed this tool to rate the patient's actual recovery.

Patients completed the expectation measure at each of the assessment periods (T1-T3). Patients were blinded to their previous rating at each assessment. A health professional assessment of the patient's actual recovery was rated by the authors who were also blinded to the previous assessments. Recording of the data took place over a 16-week period at T1 (discharge), T2 (8 weeks) and T3 (16 weeks). Patients were assessed in their place of residence from T2 to T3. Details of demographics, functional state assessed with the Barthel ADL measure (BI) (Mahoney and Barthel 1965), mood subjectively assessed with the Geriatric Depression Scale (GDS-15) (Sheikh and Yesavage 1986) and the AMT assessed cognition ( Hodkinson 1972) were also recorded.

Box 1 Patient/health professional expectation scale

| Expected mobility       | Independence | Dependent | | Expected speech  | Normal | Abnormal | | Expected personal care | Independent | Dependent |

statistical analysis

The demographic characteristics of the patients, as well as the patient and health professional expectations, were summarised with descriptive statistics. Pearson correlations were used to test for the
strength of linear association between variables along with paired t–tests, Wilcoxon non parametric paired tests and multiple linear regression when appropriate. Statistical significance was defined as p <0.05. All of the results were analysed by the SPSS version 9 software package. The local hospital ethical committee approved this study.

results

Overall, no association with depression and unfulfilled patient expectation of recovery was found in any of the areas investigated by the patient expectation measure. However, it appears that expectations, either positive or negative, may offer some protection from depression and that patients’ expectations are at odds with health professionals’ assessments. The demographic details, assessments and length of stay in hospital of the patients are given in Table 1.

mobility

Patients’ expected mobility and their actual mobility (rated by health professionals) in terms of independence or dependence at discharge (T1), 8 weeks (T2) and 16 weeks (T3) are given in Table 2.

From T1 to T3 significantly more patients perceived that they would return to full mobility (p <0.001). Professional assessments of the patients’ actual mobility was lower (p <0.05). Health professional assessment of actual recovery of the patients’ mobility increased significantly between T1 to T3 (p <0.05). Functional ADL (BI) significantly improved from T1 to T3 (p <0.001). Multiple regression analysis, with the dependent variable being patient expectation of mobility recovery, demonstrated that higher BI scores were predictive of independent mobility and less depressive symptoms at T1 (BI, p <0.014; GDS-15, p <0.017) and T2 (BI, p <0.008; GDS-15 p <0.029). Increasing age was also a significant predictor of greater expected dependence amongst the patient group from T1 to T2 (T1, p < 0.012; T2, p <0.041). Health professionals’ assessments found that increasing age was predictive of greater dependency (T1, p <0.0001; T2, p<0.017).

personal care

Patient expectations of being fully independent in their personal care and their actual independence between T1 to T3 are given in Table 3.

The expectations of patients and their actual personal care did not differ at T1 (p >0.05). At T2 and T3 patients’ expectations of independence significantly increased (T1–T2 p<0.001; T1–T3 p <0.002). However, their actual ability to independently attend to their personal care did not change (p >0.05). From T2 and T3 significant differences were reported between patients’ expectations and their actual independence in attending to their personal care (p <0.05).

depression, speech and language, cognition

Between T1 and T2 significantly more patients reported more depressive symptoms (p <0.006). Employing multiple regression analysis, with depression as the dependent variable, demonstrated that increasing length of stay in hospital was predictive of depressive symptoms at all assessment periods (T1, p <0.0001; T2, p <0.03; T3, p <0.04). From T1 to T3 no significant associations (p >0.05) with mood and patient expectations were observed. Speech and language and cognitive functioning were not associated with patient expectations either positively of negatively between T1–T3 (p >0.05).

discussion

This study did not support the hypotheses that if unrealistic expectations of full recovery from a stroke are not fulfilled the patients are likely to become depressed. Furthermore, no associations were found with expectation of recovery and speech and language dysfunction and cognitive functioning. The latter could be accounted for by the fact that those patients with significant speech and language difficulties and cognitive problems were excluded from the study. There was, however, evidence to suggest that patients were offered protection from depressive symptoms if they were optimistic
of a full recovery and had a better mobility. Why patient mobility improved significantly post discharge despite the individual's ability to attend to their personal care needs remained unchanged is a curious finding. It may be that patients have greater control over their mobility compared to their personal care and hence carers may be inadvertently attending to these needs, not realising that they are increasing the dependence of their partners.

There was a conflicting relationship between patients' overall high expectations of returning to their pre-stroke physical and personal care functioning, compared with what they actually achieved. Patients have had an expectation of recovery because they were treated in a specialist stroke rehabilitation unit and therefore may have gained the impression that their prognosis would be more favourable. The health professionals may have also given patients the unrealistic impression that in time they would make a full recovery. This argument is supported in one recent study where the expectations of older patients in a specialist unit were mismatched with their actual recovery (Dady and Rugg 2000). However, how individuals cope may influence their ability to adjust to a chronic illness and may explain why the patients in this study appear to have unrealistic expectations of recovery (Moos 1977, Billings and Moos 1981, Ehmann et al 1990, Herrmann et al 1997). Patients may use more avoidance or denial, as a means of coping with their illness instead of continually trying to reappraise a situation in which there is a poor prognosis (Miller 1992). The relationship between stroke, outcome, recovery, patient characteristics and expectations is clearly not linear and a qualitative grounded theoretical framework approach may be one way in which to try to understand these complex interactions and themes.

It is also important to consider the methodological weaknesses of this study. The small sample here lacks statistical power and, as such, the results could be reporting Type II error. A larger sample may demonstrate significant differences where none were observed in this study. It is also accepted that most recovery post stroke occurs at six months and consequently the duration of this study (16 weeks) may have been insufficient to detect the influence between patient expectation and depression. The questionnaire may also have been too insensitive to detect any change over the study period. Comparing the patient expectation measure to existing measures of patient satisfaction, health-related quality of life, apathy, anxiety or coping measures might have also provided us with explanations why these patients have unrealistic expectations of recovery after stroke.

**Conclusion**

This study provides some evidence that patient expectation as an outcome variable is independent of patient characteristics and more formal standardised assessments. Patients' subjective expectations of physical recovery post stroke need to be taken seriously as an outcome measure in the rehabilitation and post rehabilitation period.

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**Peter Hobson BSc (Hons) is senior research officer, University Department of Geriatric Medicine (North Wales)**

**Glan Clwyd Hospital, Rhyll**

**Josie Wray RGN, sister, ward manager, Stroke Rehabilitation Centre, HM Stanley Hospital, St Asaph, Denbighshire**

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**References**