

Improving stroke patients' care: a patient held record is not enough

ABSTRACT

Stroke patients received poor information and explanations regardless of whether they received a PHR. A PHR did not appear to improve patient satisfaction or discharge planning, and may have reduced opportunities for communication and explanation.

INTRODUCTION

Introduction Poor communication and lack of information are among the most common complaints of people with stroke. Stroke services are poorly organised in many countries with a lack of continuity of care between hospital and community. Consequently it is not surprising that dissatisfaction with services, especially those received after discharge, is common. Patient held records (PHRs) exist in a variety of formats and have been used in many different settings. Individualised information booklets have been used with stroke patients before, but do not provide a continued record of care, their sole role being to provide information. In other areas of health care, patients are enthusiastic about holding their own records since they allow access to information, increase autonomy and bring about a shared feeling of responsibility for health. PHRs have not been evaluated for use with stroke patients before. A PHR might benefit stroke patients by providing information, promoting a more active role in their care and the possibility of contributing to decision making. As many people are involved in the care of stroke patients, possession of a PHR might give patients the confidence to ask questions of staff and they might receive more explanation. A PHR used by all members of the rehabilitation team, both in and out of hospital, could improve communication between team members. Consequently, our main hypothesis was that stroke patients with a PHR would be more satisfied with their care and would receive better planned care than those without a PHR.

CONCLUSION

We expected the PHR to bridge the gap between hospital and the community, contributing to the continuity of care that has been found elsewhere. This did not occur and our findings highlight the generally high levels of dissatisfaction with services received after leaving hospital. Introducing a PHR into stroke care, an area of health care recognised to be haphazard and fragmented, was an ambitious undertaking. Changing the well-established culture and practice of stroke patient care will take more powerful interventions than a PHR. PHRs have been shown to be effective in some clinical settings but such findings are not applicable to the more difficult circumstances of the acute hospital care of frail and often confused patients. This study has drawn attention to the generally poor levels of information and explanation given to patients and their lack of involvement in their care, regardless of whether they had a PHR.