The palliative care needs of acute stroke patients: a prospective study of hospital admissions

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Abstract

Background: despite a mortality rate of approximately 30% in acute stroke, little is known about the palliative care needs of this group of patients.

Design: prospective study of 191 acute stroke patients admitted to hospital in England. Biographical, medical and stroke-related data were collected. Participants completed the Sheffield Profile for Assessment and Referral to Care (SPARC), a screening tool for referral to specialist palliative care.

Findings: over 50% reported moderate to significant fatigue-related problems. Approximately 50% reported symptom-related problems (e.g. pain) or psychological distress (e.g. anxiety). Approximately 25% had concerns about death or dying, and 66% had concerns about dependence and disability. Over 50% were worried about the impact of stroke on family members. There were significant main effects of dependence (Barthel Index) \(F^{(1,123)} = 12.640 \quad P = 0.001\) and age \(F^{(4,123)} = 3.022 \quad P = 0.020\), and a significant three-factor interaction between dependence, age and co-morbidities \(F^{(9,123)} = 2.199 \quad P = 0.026\) in predicting total SPARC scores.

Conclusions: acute stroke patients have a high prevalence of palliative care needs. Acute stroke services should use the SPARC for needs assessment. Priority for assessment should be given to patients with a score of <15/20 on the Barthel Index, a tool already used in most stroke services.

Keywords: stroke, palliative care, needs assessment, elderly
Introduction

Over 130,000 people in the United Kingdom have a stroke each year, three-quarters of whom are aged over 65. Stroke is the third most common cause of death in the United Kingdom and the single most common cause of severe disability. The ‘acute’ stroke phase is defined as the first 30 days after stroke, during which nearly one-third of patients will die [1].

The UK stroke service model [2] reflects international principles of good practice including rapid admission to specialist, hospital-based stroke units, early access to specialist rehabilitation services, the transfer of ongoing inpatient rehabilitation into community settings and a range of long-term health and social care services that support life with stroke.

The National Clinical Guidelines for Stroke [3] and National Stroke Strategy [2] recommend that all stroke patients should have access to specialist palliative care expertise and that staff providing this care receive appropriate training. Within cancer, palliative care is defined as the alleviation of pain and discomfort when a cure is not possible [4], and can be an important component of a range of health care services, whether patients are terminally ill or not, and in diseases other than cancer [5, 6]. As the stroke disease trajectory is variable, the challenge is to identify models of practice that support the timely integration of palliative care.

The end of life care tools to guide practice recommended in the End of Life Care Strategy [7] include the Liverpool Care Pathway (LCP) [8] providing generic recommendations for terminal care. The applicability of the LCP to acute stroke has not been systematically evaluated, although it may improve prescribing practice and communication about prognosis [9]. The Macmillan Gold Standards Framework [10] supports the strategic evaluation of palliative care in community services, and the Preferred Priorities of Care tool [11] supports advance care planning. Whether these strategies address the clinical challenges of embedding palliative care in acute stroke services, such as difficulties in accurate prognostication, has yet to be tested.

Prospective information on the palliative care needs of stroke patients is lacking. A critical review of the international literature [12] identified seven studies, four of which were completed within the United Kingdom. Many patients did not receive optimal symptom control. Patients reported insufficient help to overcome psychological morbidity, and informal caregivers identified difficulty accessing information. The caring experience was distressful and unrewarding, with high reports of insufficient help. The review concluded that palliative care may have a role in the care of stroke patients and should be systematically provided on the basis of need.

The National Clinical Guidelines for Stroke make no distinction between those patients who die in the acute and later stages of the disease pathway, although these groups may require different palliative care strategies and interventions. In non-acute stroke, patients have some time to make plans for death, and professionals have opportunity to implement appropriate interventions. This study focuses on the palliative care needs of acute stroke patients about which little is known.

Methods

Aim

The aim of this study was to identify the palliative care needs in a consecutive cohort of acute stroke patients. The local ethics committee approved the study.

Study population and sampling

Within one UK city, all acute stroke patients admitted to either of two acute hospitals were eligible for inclusion in this study. Stroke was confirmed by CT scan. Children and patients with subarachnoid haemorrhage were excluded. Patients with a serious psychiatric illness or severe dementia were excluded if no family member was available to provide consent.

The study benefitted from the use of a centralised stroke register. After admission and initial confirmation of diagnosis, all patients were seen by a stroke specialist nurse who commenced the integrated stroke pathway, consisting of protocols for all aspects of multi-disciplinary acute, rehabilitation and transfer of care. Stroke Specialist Nurses provided patients or family members with a study information sheet. Twice weekly, they informed the research team of those patients introduced to the study for follow-up and recruitment. A researcher then visited or telephoned the patient (or their family member) and arranged a suitable time to discuss the study and take consent. If it was not possible to approach the patient directly (for example, if the patient was unconscious or had cognitive difficulties), a family member was approached. Witness consent was available where it was not possible for the patient to give written consent.

Recruitment ran from October 2006 to June 2007, during which attempts were made to recruit all acute stroke admissions. Recruitment was regularly reviewed to ensure the study sample was as consecutive as possible.

Data collection

Biographical data, medical history and stroke-related data were extracted from patients’ medical records on recruitment. The Barthel Index [13] assessing functional dependence was completed by stroke unit staff and cut-offs (1–14; 15–20) used to identify levels of disability.

Palliative care needs were assessed using the Sheffield Profile for Assessment and Referral to Care (SPARC), developed to screen patients with advanced illness, regardless of diagnosis, for specialist palliative care referral [14, 15]. The SPARC supports clinical decision-making rather than providing a quantitative indicator of whether referral is warranted. Tool development was underpinned by an extensive literature review and interviews with patients and
refined through testing in patients referred to specialist palliative care services [15]. It is composed of five domains:

- physical symptoms (21 items)
- psychological issues (9 items)
- religious and spiritual issues (2 items)
- independence and activity issues (3 items)
- family and social issues (4 items).

Each item is scored on a four-point scale according to how participants have been affected by each issue in the previous month. Two items relating to problems with mobility and fear of falling were added. The mean length of time from admission to hospital to completion of the SPARC was 7.77 days (SD 7.55 days). The SPARC was completed by patients as a questionnaire or by interview with a member of the research team. Where patients were unable to complete the SPARC, a close family member was asked to complete on their behalf.

Fifty-nine (31%) assessments were completed in this way. Due to the complexity of stroke-related impairments, using carers as proxy raters is a feature of applied stroke research, although there is a tendency for carers to rate functional problems higher than patients [16]. In palliative care research, carers can be a vital source of non-clinical data. Whilst agreement in subjective aspects of the patient’s experience can be problematic, carers can provide reliable information on service quality and observable symptoms [17].

Data analysis

Descriptive statistics and graphical displays provided a prevalence assessment of palliative care needs in patients with acute stroke. Predictors of need were identified using multiple regression (Enter method) and explored using General Linear Modelling techniques.

Results

Study sample

A total of 290 patients were introduced to the study, of whom 191 stroke cases were recruited (Table 1). The age (25.7% aged <65 years) and gender profile of participants is typical of the acute stroke population. Reasons for non-recruitment were lost to follow-up (13, 4%), declined (28, 9%), died before consent could be taken (24, 8%), cognitive impairment with no family member (15, 5%), incorrect diagnosis (12, 4%) and rapid discharge (7, 2%).

Profile of needs and problems

The proportions of participants for each level of severity on SPARC items within each domain are summarised graphically in the Supplementary data available in Age and Ageing online.

The SPARC physical domain appeared to be sensitive: although a considerable prevalence of problems and needs was evident, only approximately 10% report any other ‘un-controlled symptoms’. Nearly 80% experienced some form of communication problem. Fatigue-related problems were prevalent, with over 50% reporting moderate to significant problems with ‘feeling weak’, ‘feeling tired’ or ‘being sleepy during the day’. Approximately 50% reported problems with ‘pain’, ‘memory loss’, ‘headache’, ‘restlessness’ or ‘bladder problems’. The additional two items indicated that mobility problems were highly significant, which combined with speech problems, represents the clinical picture. Forty percent had moderate to significant ‘fear of falling’. Mirroring the prevalence of fatigue-related concerns, 70% reported problems with ‘feeling everything’s an effort’.

Approximately half experienced some form of psychological distress such as ‘anxiety’, ‘low mood’, ‘confusion’, ‘poor concentration’ and ‘loneliness’.Whilst the prevalence of religious or spiritual concerns was low, approximately 25% had concerns about death or dying. Approximately two-thirds had concerns relating to dependence and disability. Over 50% were worried about the effects of their stroke on others within their support network. Twenty five percent felt that they needed more help than their family could provide.

Predictors of need

Patient dependence was a significant predictor of scores on physical, psychological, and religious and spiritual SPARC domains, and with female gender and age, on the dependence and disability domain. Higher levels of dependence and female gender were associated with greater concerns

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TIA, transient ischaemic attack.
about dependence and disability. Those patients under 55 years of age and those over 75 years of age also had a higher prevalence of these problems. Patient dependence, female gender and the number of co-morbidities were significant predictors of scores on the SPARC family and social domain.

A model of the data was constructed using the four factors shown to be significant within the regression. This confirmed the significant main effects of the Barthel Index score ($F^{3,123} = 12.640\ P = 0.001$) and Age ($F^{4,123} = 3.022\ P = 0.020$) in predicting total SPARC scores. The model also indicated a significant three-factor interaction between Barthel Index, Age and Co-morbidities ($F^{9,123} = 2.199\ P = 0.026$).

**Discussion**

We aimed to prospectively investigate the palliative care needs of a cohort of patients admitted with acute stroke. Our pilot study highlighted that many stroke service staff equate palliative and terminal care. Nurses were reluctant to refer patients to the study until they appeared virtually moribund. We excluded ‘palliative care’ from subsequent study material, with the approval of the ethics committee.

We succeeded in assessing a sizeable cohort of patients within 1 week of admission, which we are confident is comprehensive and unbiased, and typical of UK acute stroke services.

Our study sample was representative of age and gender. Our findings may be different for religious and socio-cultural groups: we recruited few participants from ethnic minority groups within this study. A total of 47.6% of the cohort lived alone. Current demographic shifts in the age of the UK population, alongside increased mobility and cultural diversity, are leading to structurally and geographically dispersed families. Consequently, single-person households are increasingly common; older women are more likely than older men to live alone [18].

As stroke policy emphasises rapid access to specialist services [2], more patients with severe stroke are likely to be in hospital requiring palliative and end of life care. Using a validated tool to identify palliative care needs, we identified a wide range of needs, with significant proportions of patients experiencing them.

Nearly 80% experienced fatigue-related symptoms. This challenges the shift towards more intensive and early mobilisation after stroke [19] and early supported discharge [2]. Similar proportions experienced some form of low mood, anxiety, confusion or poor concentration. In addition, nearly one in five patients expressed some suicidal feelings. In comparison, 20–30% of patients with advanced cancer have a formal psychiatric diagnosis, the most common being depression [20]. This suggests the importance of providing opportunities for patients to express their distress and access to specialist mental health services.

Studies have demonstrated patients’ fears about feeling a burden to others, including family members [21, 22]. Whilst 80% felt that family support was sufficient, it should be noted that our sample was hospitalised. The impact of the challenges faced by patients and families during transfer of care and renegotiating life with stroke in community settings may not have begun to be felt.

Lower physical independence is associated with problems identified by the SPARC. Female gender and age (both young strokes and those aged over 75 years) are also associated with concerns about dependence and disability. Female gender and the presence of co-morbidities are associated with higher levels of family and social concerns. Our data suggest that the influence of co-morbidities is nonlinear: patients with no or multiple co-morbidities experienced greater problems. This possibly reflects the development of coping strategies by those with multiple co-morbidities and differs from the results of previous studies [23].

Whether we can extrapolate the problems identified in this study to a need for specialist palliative care requires careful consideration. Evidence and policy now recognises the need for a range of health and social care services to ameliorate the full range of stroke sequelae [2, 3]. Research has identified the need for the integration of palliative care within a range of conditions with high morbidity including heart disease [24, 25], chronic obstructive pulmonary disease [26], end-stage renal disease [27] and chronic illness [28]. Many of the problems identified within this study are part of both the palliative care and stroke literatures. For example, post-stroke fatigue is a well-documented problem, associated with a high case fatality [29]. In the absence of models to explain the mechanisms of post-stroke fatigue, both palliative care and rehabilitation perspectives may reduce its impact and warrant further investigation.

The problems identified by patients or proxies in this study do not, of course, imply that these are palliative care needs, or that a generalist model of palliative care within the acute stroke service, or referral to peripheral specialist palliative care services is required. The SPARC does not provide a threshold score or problem profile which is indicative of the need for specialist referral. This may be a useful line of enquiry in further research, requiring follow-up of patients and care processes over time, as needs change.

Lack of capacity within specialist palliative care [30] underpins the aim of the NHS End of Life Care Strategy [7], enhancing the quality of generalist palliative care. Embedding a generalist model of palliative care in non-cancer services requires a debate about the capacity and capability of the generalist service to address the needs and concerns of patients and families, clarity about the timing of engagement with specialist services and the development of practice tools to support model implementation.

**Conclusion**

Acute stroke patients have a high prevalence of problems which may be met by the integration of principles of palliative care into stroke services. The incorporation of a targeted
needs assessment is a useful first step in the refinement of a generalist model of palliative care for acute stroke. We recommend the SPARC as the basis for needs assessment for those patients with a score of less than 15 on the Barthel Index, a routine assessment already used in most stroke services. This will serve as a prompt for staff to consider palliative care issues, facilitate dialogue between staff, patients and families and, importantly, opens up possibilities for discussion of sensitive issues including fears about death and dying. Whilst some of the patient needs identified within this study are also recognised within the stroke literature, for example post-stroke fatigue, there is a need to investigate a combined approach to management, integrating principles of rehabilitation and palliative care.

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**Key points**

- The palliative care needs of acute stroke patients are poorly understood.
- A screening tool for referral to specialist palliative care indicated a high prevalence of needs in this patient group.
- Priority for assessment should be given to patients scoring <15/20 on the Barthel Index.

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**Supplementary data**

Supplementary data mentioned in the text is available to subscribers in *Age and Ageing* online.

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**Acknowledgements**

We wish to thank all the patients, families and staff who supported this research and to the Stroke Association for funding this study.

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**References**

CRP: a biomarker for early detection of bacterial infection

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Abstract

Background: although C-reactive protein (CRP) is widely used in younger populations, its value for diagnosing bacterial infection in older population is not well established. This study examined the usefulness of serum CRP level in the early detection of bacterial infection in older patients.

Methods: in a prospective cohort study, consecutive patients aged 70 years or over admitted to Aged Care wards were recruited. CRP levels were measured within 24 h of presentation, and their significance in predicting bacterial infections was analysed. The relationship between CRP and other clinical features of diagnosing bacterial infections (e.g. temperature, white cell count, neutrophil count, oxygen saturation, blood pressure and heart rate) was also examined.

Results: a total of 232 patients were recruited over a period of 3 months. CRP levels were 21.3±36.0 and 150.5±114.1 mg/l (mean±SD) in the non-infection and infection groups, respectively (P<0.001). We found that the CRP cut-off value of 60 mg/l had the best combination of sensitivity and specificity. At this level, the sensitivity of diagnosing bacterial infection was 80.7%, specificity 96.0%, positive predictive value 91.9% and negative predictive value 89.8%. CRP and temperature had higher sensitivity and specificity than white cell count and neutrophil count in the diagnosis of infection. For every 1-mg/l increment in CRP, the risk of bacterial infection increases by 2.9%.

Conclusion: CRP is a convenient and useful biomarker to predict early bacterial infection in older patients especially when other markers are atypical or not present.

Keywords: bacterial infection, C-reactive protein (CRP), elderly, older person