

# Palliative care in stroke

Palliative care aims to improve the outcome of patients, especially in life threatening conditions. This is usually provided through prevention and relieving of suffering by a holistic approach; considering the physical, psychosocial and spiritual modes of treatment. The chronic diseases are insidious in onset and are preventable; they contribute to a high mortality and morbidity in the developed world.<sup>1</sup> In part two of this article we review the evidence base for palliative care for stroke patients.

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Stroke is a major health problem worldwide and has a huge impact on a patient's life. It affects approximately 160,000 people in England every year, causing high mortality and morbidity. It is the third most common cause of death in the UK, with 26,400 people dying each year and costing the NHS approximately £2.8 billion. Around one third of patients die in the first month after a stroke and most within the first 10 days.<sup>1</sup> It is estimated that approximately 40% of the patients with stroke do not fully recover and many are transferred to care homes permanently. Once stroke develops they require complex care as complications can lead to long-term disability. Thus, regular input is required from a multidisciplinary team so that the appropriate care can be provided to the patient.

The provisions of palliative care for stroke patients are complex, and require an appropriate input from the clinicians. It helps to understand the psychological and spiritual wellbeing of the patient rather than only physical needs. It is necessary

that we assess those interventions, which help in supportive and palliative care provision, so that if the need arises they can be implemented. The palliative care provision to stroke patients should give a clinical benefit in all aspects and be cost effective.

## Evidence: last year of life

There are number of issues during the last year of life as mentioned in box 1, but there is limited evidence to support these issues. RSCD was a study based on retrospective interviews with secondary data being analysed.<sup>2</sup> The RSCD survey described the last year of life of a random sample of patients who died of a variety of causes including stroke. More than half of the patients reported pain (65%), mental confusion (51%), depression (57%) and urinary incontinence (56%) in the last year of life.

The results suggested that many patient's who died of stroke, did not receive optimal symptom control, psychological support or

enough choices about their care. It can be argued that the respondent's views may be different from the patient's themselves, and dependent upon the effect of bereavement, on how much care, before the patient's death, is remembered by the carer. The above study also concluded that improving symptom control and psychological support for patients who die from stroke are needed. It emphasised the need for better communication between health workers, patients and their families. Furthermore, it highlighted the importance of palliative care to doctors and nurses. This ensures that dying patients receive high quality care.

Another study conducted in Perth, Western Australia, looked at the population based assessment of the impact and burden of care given to long term stroke survivors.<sup>3</sup> The multidimensional outcomes measured were used to assess the physical, cognitive function, psychiatry morbidity and symptomatic behaviour of the patients at uniform intervals during the one year follow up period. The

### Box 1: Recommendations about future care

#### Identify and manage different components of care

- End of life
- Last year of life

#### Training of stroke team and identify

- Needs of the patient
- Needs of the carer

#### Research

- Randomised studies
- Longitudinal and prospective studies

#### Support of carer

- Communicating on a regular basis
- Awareness about the complications in future care
- Financial and psychological support.

researcher also assessed the effects on informal carers on their lives at one year, looking at the impact and burden associated with giving care. The impact on the caregivers' life was assessed in accordance with the Social Behaviour Assessment Schedule (SBAS).<sup>4</sup>

A total of 84 stroke patients were included after considering inclusion and exclusion criteria along with their carers, until one year after stroke. Almost 80% of carers reported emotional ill health and the disruption of their social life. It was common for carers to report that patients were apathetic, indifferent, irritable, and depressed with no motivation after stroke. This led to a complete lack of confidence, especially for going outside the home environment.

This study identified that stroke outcomes cannot just be assessed on the effects of a patient's life, but also how it impacts on a carers' life.

This study included a small number of participants with no comparative group in which carers were not involved. Thus, it is difficult to conclude that stroke related disability has a differential effect on carers. Further, the study used an assessment scale, which has not been validated on stroke patients, so the interpretation could be erroneous.

Impact and stress are subjective; one cannot exclude the possibility that associations between variables were spurious or that some were overlooked because of various confounding effects of the interview.<sup>5</sup> A comprehensive stroke service should make sure that continuous and coordinated care is provided across various sites through an integrated multidisciplinary team.<sup>1</sup>

Carers need information about stroke related problems affecting them as well as the patient and support available in the community. Thus, making sure that patients with stroke related disabilities are able to live at home as long as possible by providing adequate support to carers looking for intermittent respite care for the patient. It was clear from the above study results that stroke outcomes cannot be assessed simply by looking at the effects on patients but also those effects associated with a high risk of disrupting the integrity of families and the quality of life of caregivers.

#### Pain

Pain is a common physical symptom after stroke. Studies of pain in stroke survivors have

been concentrated on a clinical diagnostic perspective, and not on the intensity of the pain. Jonsson et al assessed the prevalence and intensity of pain after stroke, focusing on the patients' perspective.<sup>6</sup> 297 survivor patients who were able to be assessed on the visual analogue scale of pain at both follow up assessments at four and 16 months were included. In this study more than 90% of the patients could be followed up, as one third of the patients could be followed up in the community.

The results showed that half of the patients with moderate to severe pain at the initial stages after stroke had no pain on subsequent follow ups. The prevalence of pain after stroke decreased with time. Only 20% of the patients had moderate to severe pains after 16 months. The patients, who were in pain at 16 months, had more severe pain, which profoundly affected their well being. This was a prospective study using a well-standardised scale for assessment. There were two designated health professionals responsible for the follow up assessment so that uniform standards could be maintained. This study did not provide information about the type and dosage of analgesic used during the follow up. The psychological aspect was not taken into account.

#### Daily living

A postal survey done by Teno et al focused mainly on the activities of daily living and mobility in the last year of life.<sup>7</sup> It included 3614 participants, who were next of kin of the patients who had died. Out of these deaths, 12.5% were due to cerebrovascular events.

In contrast to patients with cancer, patients who died of

stroke had a high baseline level of functional impairment. This impairment gradually increased in the last five months of life. A similar situation was noted in mobility. The sample size was large in comparison to other studies, allowing results to be statistically significant. As this was a retrospective study with no direct participation by patients, the results could be biased and erroneous.

### Palliative care in non-malignant conditions

Specialist palliative care in non-malignant disease is becoming more popular as more evidence emerges. The secondary analysis of RSCD provided more evidence about non-cancer specialist palliative care.<sup>8</sup> Thus, helping in the development of services, which are appropriate and cost effective.

The non-cancer patients were selected who had similar physical and psychological symptoms as those experienced by cancer patients. Informal carers were asked whether the deceased had any symptoms varying from difficulty in breathing to anxiety and how stressed they felt about it. Using the selection criteria based on these symptom experiences, 16.8% of the total non cancer sample was selected. This data was then combined with data on the number of deaths from each cause in England and Wales. This helped in estimating the number of people each year, which had severe symptoms in their last year of life. The selected non cancer patients were aged 85 years or over at death, lived alone or in care homes and died in hospitals.

It was a retrospective study

with a small sample size, relying more of the informal carer's judgement and views than the patient's. The RSCD did not collect any information from medical records. Thus, the results are the views of informal carers, which could be their personal judgement. These results are hypothesis generating, rather than definite, and further research is needed. Over half of the non cancer patients were aware that they were likely to die. This perception was by patient judgement rather than explained by a health professional. This may be due to difficulties in assessing a prognosis in non cancer patients compared to the cancer group. Further work is needed to explore how much information should be given and the ways it should be given, keeping in mind the difficulties in estimating an accurate prognosis of the condition.

Further analysis suggested that cares given to non-cancer patients is quite sub optimal compared to that given to cancer patients. Non cancer patients also need expertise in symptoms control, open communication about death and encouraging patient and family autonomy. We need further randomised studies so that we can develop a better understanding and plan our future care accordingly.

### Liverpool Care Pathway

The role of the LCP as an evidence based tool for dying patients was assessed.<sup>9</sup> This was an audit, conducted by reviewing case notes of 20 consecutive patients, before and after the implementation of the LCP. There was a marked improvement in the documentation of patient care in around six

of the seven key areas assessed (discontinuation of inappropriate drugs, nursing interventions, subcutaneous medication written up as per protocol, the patients religious needs assessed/ documented and discussion with the next of kin regarding contact at the point of the patient's death). The only area, which did not show improvement, was that family members were unaware that their relative had entered the dying phase.

The sample size was small and patients were not included from the entire region. More randomised evidence is needed suggesting that it can work in all acute stroke units keeping definite inclusive and exclusive criteria.

### Palliative care in stroke

Stroke results in high morbidity, mortality and may cause a range of distressing symptoms during the dying phase. Once it is felt that death is inevitable, stroke patients have to be managed appropriately. They may require a physical, psychological, social and spiritual input. The Royal College of Physicians have recommended that staff providing palliative care for patients after stroke should be trained in the principles and practice of palliative care. All stroke patients should have access to specialist palliative care expertise when needed. The End of life decisions to withhold or withdraw life-prolonging treatments should be in the best interests of the patient.

The local services need to identify the needs of existing specialist palliative care and training for the stroke team so that they have the right palliative care

skills. They should be able to work for the benefit of the patient by sharing skills and knowledge from other health workers.

The end of life care for stroke is not uniformly accessible to all patients. It is variable depending upon which hospital the patient is treated at. The need of care is inadequately assessed. The patient's choices as well as death are often not discussed by professionals. There is a need to establish mechanisms to ensure that each patient receives care in accordance with the care plan. Services have to be coordinated across the health services so that policies and guidelines are implemented uniformly and an evidence based practice can be provided to each and every patient under that umbrella. The LCP is being adopted increasingly where dying is diagnosed, irrespective of the place where the patient may be dying. Informal carers have a vital role to play in supporting those at the end of their life. They should be involved from the beginning about the prognosis, decision making and in changing circumstances.

## Recommendations

The principles of specialist palliative care should be practised in each stroke unit or in the community, especially during the last year of life. There should be a multidisciplinary approach in deciding about future care with a view to share knowledge and skills with other co-health workers. The development of simple assessment tools and integrated care pathways should be developed so that an excellent quality of palliative care

can be provided.

Further research is required so that the appropriate ways of delivering care and the optimum means of collaboration with specialist palliative care staff can be planned. The randomised studies should be conducted so that the best evidence can be incorporated into clinical practise.

The carer's welfare should be considered at each stage and all possible support should be provided in the community. Adequate and timely professional support is required if caring is not to become an intolerable burden for informal carers. The integration of services is necessary so that stroke patients and their families get palliative support, irrespective of their place of care.

## Conclusion

Like any other chronic illness, it is difficult to pinpoint an accurate prognosis in stroke. The expertise in palliative care is mainly cancer based and modifying the principles so that it can be provided to stroke patients in an effective and realistic way is a big challenge. Specialist palliative care comprises of complex interventions. It becomes exceedingly difficult to ascertain which intervention will provide the best clinical or cost effective benefit to the stroke patient. The LCP is widely used in dying patient after an acute strokes, so that the principles of palliative care can be practised. The information about palliative care in stroke is limited, but with the intercollegiate guidelines in 2004, clinicians are now aware about the palliative role and are incorporating it into their clinical practise. There

needs to be a range of strategies and interventions, which can be implemented in the last year life of stroke patients. Further studies are needed to explore the experiences of stroke patients who die and their families in more detail and to identify and evaluate effective ways of meeting their needs.

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