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.\(^1\) In this two part review, we look at palliative care in stroke.

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Chronic diseases represent the modern epidemic, where treatment options are exhausted and patients pass from the chronic illness phase to the terminal stage. There is evidence to support the notion that these patients require a palliative approach, even though they have non-malignant conditions.\(^2,3\)

The emerging evidence suggests many health issues of the non-malignant condition are the same as those experienced by cancer patients towards the end of their life.\(^4\) Palliative care has become important in the care of chronic illness in the last decades.\(^5\) There are similarities between the palliative care needs of patients with chronic illness and cancer patients such as physical symptoms, psychological and spiritual needs.\(^6\) However, there are some distinct differences as well. The trajectory of chronic illness is prolonged, compared to a cancer patient although they may have the same palliative care needs.\(^7\)

Chronic illnesses typically affect the physical and psychosocial wellbeing of a patient at an earlier stage than to cancer patients. This leads to the progressive deterioration in their health and wellbeing until the end of their life.\(^8\)

Generally, it is difficult to switch from therapeutic treatment to palliative treatment in a chronic disorder management. This may be due to the diagnostic uncertainty and unpredictable prognosis for the individual patients, the lack of right exposure, training among health workers and limited resources.

Patients with non-malignant conditions have frequent episodes of illness requiring hospitalisation, but the bulk of their care can be provided at home. The integration of service need is important to provide optimal care to these patients.\(^9\) Once the therapeutic option is exhausted in a chronic illness, the clinician should discuss a palliative and supportive care approach at an earlier stage in a concerned fashion so that patients are aware about the outcomes and can plan their life accordingly. The specialist care should be structured around the needs and problems of the patient.

Even dying patients need improved symptom control; better nursing care and open communication about death and dying.\(^10-12\) In 1992, an expert report recommended palliative care should be available to all patients who need it, irrespective of the diagnosis. Only 4% of the patients with non-malignant conditions were admitted for the first time to a hospice or a specialist palliative care unit in 1994–95 despite the fact that these units claimed they would accept referral for these patients.\(^13,14\) Patients with non-malignant conditions are older and also have different dependency patterns.\(^15\) Many of these terminally ill patients are too ill to participate in any type of research or they are still having active treatment, so are excluded from research.\(^15\)

Stroke

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.
**Box 1: Complications of stroke.**

**Pain**
- Aspiration pneumonia
- Incontinence of urine/bowel
- Pressure sore
- Loss of mobility/Contracture
- Recurrent fall

**Psychological**
- Depression
- Dementia
- Lack of emotional support

**Social**
- Dependent on daily activities
- Lack of financial support

**Impact on family and carer**
- Job issues for informal carer
- Loss of income
- Physical strain
- Psychological vulnerability
- Limited social life
- Reduced happiness

Around one third of patients die in the first month after a stroke and most within the first 10 days. The cerebrovascular diseases account for 12% of all deaths. The relative risk of death after a stroke compared to the general population is about 20 times for those over 60 years and doubles for patients over 70 years.

Australian studies have reported that five years after a stroke, 40% of patients were still alive, with half of these disabled or dependent. The literature on prevention, treatment and rehabilitation exists, but little evidence is available about the role of palliative care in dying stroke patients. We know that in developed countries with ageing populations, the incidence of stroke will increase in direct proportion to the age and the majority of the patients affected are above 65 years. It is a prime cause of disability, leading to a permanent residual deficit, which affects them physically and psychologically, leading to a major impact on both the family and society.

It is estimated that approximately 40% of 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 (Box 1). Thus, regular input is required from a multidisciplinary team so that the appropriate care can be provided to the patient.

**Palliative care and stroke**

The awareness about palliative care in stroke is very limited amongst clinicians. Recently “National Clinical Guidelines for Stroke” recommended that all patients with stroke should have accessibility to palliative care if needed and health workers involved in this care should undergo necessary training.

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 then 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.

The NHS End of Life Care Programme (2005) is aimed at improving end of life care to all patients irrespective of their diagnosis. This is to help those with advanced, progressive and incurable conditions to live as well as possible until they die. It identifies the needs of both the patient and family and ensures that these needs are met throughout the last phase of the patient’s life and into bereavement. The Programme rolled out a few initiatives to improve end of life care (Box 2).

The Gold Standards Framework supports the complete evaluation of palliative care in the community, to provide the appropriate care in a home set up.

The Liverpool Care Pathway (LCP) provides the guidelines to deal with terminally ill patients in an acute set up in a generic way. The LCP is a multiprofessional document that provides excellent care during the dying phase. It helps in providing guidance on the different aspects of care required including comfort measures, anticipatory prescribing of medication, discontinuation of inappropriate interventions, psychological and spiritual support. It also focuses on bereavement and support to the family members.

The Preferred Place of Care tool is a patient held document with the aim of improving services and giving patient’s choice as to where they receive their care.

**The burden of stroke in an acute setting**

A number of studies have tried to identify the total number of patients who are likely to die and then to identify how many patients may have had a stroke. However,
these studies didn’t provide the extent of palliative care required as more detailed information was unavailable. The King’s College Hospital London Palliative Care Team conducted a case notes review of a set of 553 patients in an acute hospital over three days in 1998. Sixty-four (12%) patients had advanced disease, which was no longer amenable to curative treatment and five patients had the main diagnosis of cerebrovascular disease. A similar study was also conducted in one of the acute hospitals in Sheffield. Case notes of 452 inpatients on a given day were reviewed. Ninety-nine (23%) patients were considered by staff to have palliative care needs, out of which six patients had a stroke. Similar studies have also been conducted worldwide. The overall impression is that palliative care provision for stroke patients needs to be set up, so that the optimal care for dying patients can be provided.

Informal carers

The majority of stroke survivors are provided help in the form of physical and emotional support, mainly by close family members. These carers, commonly known as informal carers are not paid but are valuable resources. As a health resource, informal carers play an important role in the successful rehabilitation outcome in stroke survivors. Patients who are poorly supported by family members have psychological problems leading to poorer outcomes.

An extensive review on informal carers was conducted in 1999 to identify all the studies considering the impact of a stroke, the factors which help in caring

Box 2: Issues during the last year of life

<table>
<thead>
<tr>
<th>Physical health</th>
<th>Pain</th>
<th>Urinary incontinence</th>
<th>Infection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>Cognition</td>
<td>Depression</td>
<td>Loneliness</td>
</tr>
<tr>
<td>Social care</td>
<td>Housebound</td>
<td>Dependent on living by carers</td>
<td></td>
</tr>
</tbody>
</table>

Spiritual

Hope is a concept that is often mentioned in the literature as a theme in the last year of life. For many people, hope is an important component of their spiritual well-being. It is often associated with the belief in a higher power or a sense of purpose. Hope can provide a sense of comfort and help in facing the challenges of the last year of life. It is important for healthcare professionals to recognize and support hope as a vital aspect of spiritual care.

In the last year of life, the focus shifts from cure to comfort and quality of life. The physical health of patients is often compromised, and they may experience pain, urinary incontinence, and infections. Psychological issues such as cognition, depression, and loneliness may also arise. Social care needs may increase, and patients may require assistance with daily living. Spiritual needs are also important, and hope can play a significant role in supporting patients through this difficult time.
for a stroke survivor and the health service provision. They could identify 29 studies exclusively on stroke carers. Review studies mainly looked at the psychological impact of caring for the stroke, using the concept of psychological morbidity and a carer burden.

The results of this study showed that the presence of behaviour, incontinence and cognitive abnormalities in stroke patients, predict carers’ emotional dysfunction. The carers’ physical health, psychological state and relationship with the stroke survivor prior to the stroke may determine the carers’ psychological state post stroke. These studies have established that caring for a stroke patient has a detrimental effect on the physical and social health of the carer. They also highlighted the fact that the use of positive coping techniques contributed to a better psychological outcome.

In a retrospective survey Regional Study of Care of the Dying (RSCD), data was collected by taking information from a randomly selected sample of people who died in 1990. This was from 20 self-selected English health districts that were in the national sample in terms of socio-demographic characteristics and healthcare provision. The respondents included 111 people with the majority of them being informal carers. Of the informants, 20% were spouses, 48% relatives, 20% officials and 11% friends or neighbours.

Two fifths of stroke patients who died needed more help with personal care, a quarter needed more help with domestic chores and a third needed more financial help. Stroke patients living in the community require more help with domestic chores, especially for personal care. Informal carers required better support, especially covering the psychological aspects. Informal carers experienced moderate restrictions in their activities. Two thirds of carers felt that their roles had an adverse impact on their lives. The data also suggested that spouses found caring less rewarding than other respondents. This could be due to the fact that spouses have lost their social companion, particularly if stroke had led to communication and cognition deficit. Thus, improved support for informal carers is required and further research is necessary to identify and evaluate effective ways of providing appropriate support in the community.

The integration of the health and social services is necessary to avoid stroke patients and their families being adversely affected by boundary disputes where neither service takes responsibility for meeting the patients’ needs.

The above study was not randomly selected, but the population covered had a similar health service provision, demographic spread and death rate. A further disadvantage of the retrospective approach is that unless patients die from disease, it is difficult to link the study population with any group of patients who can be identified prospectively. The sample size of the study was small and conducted in England only.

**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.

**Conflict of interest: none declared**

**References**

10. Addington-Hall J, Lay M, Altmann D, McCarthy M. Community care for stroke patients in the last year of life: results of a national retrospective survey of surviving family, friends
REFERENCES

1. Proctop SR DCs, Proctop 3 DCs.
3. Health Soc Care Community 1998; 6(2): 112–19