

A hope, a dream and a challenge for ASG

Palliative care

The World Health Organisation defines palliative care as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount.

The goal of palliative care is achievement of the best quality of life for patients and their families."

The main principles of palliative care are generally seen as:

- * Affirms life and regards dying as a normal process
- * Neither hastens nor postpones death
- * Provides relief from pain and other distressing symptoms

- * Integrates the psychological and spiritual aspects of care

- * Offers a support system to help patients live as actively as possible until death

- * Offers a support system to help patients' families cope during the patient's illness and in their own bereavement.

Hence we can see the emphasis on terminal illness.

However, people with non-terminal chronic, incurable illness may also be provided for in a palliative care setting; for instance, some hospices will take MS patients for respite care.

The charity, Help the Hospices (1), state:

“Hospices care for the whole person, aiming to meet all needs - physical, emotional, social and spiritual”

Patients can expect:

- * “to be valued and given time

- * to be accorded respect, privacy and dignity

- * to be responded to with empathy, especially when in distress

* to be listened to and for communication to be sensitive and honest

* to be shown understanding of your individual beliefs, lifestyle and culture."

The Hospice movement, begun by Dame Cicely Saunders in 1967, held a central aim of reducing the suffering of dying patients and their families. This was achieved by using a comprehensive approach to all aspects of the illnesses involved, seeking to ameliorate physical, emotional and social damage.

Essentially, palliative and Hospice care are seen in a context of the dying patient, whereas there is a real need for similar facilities for the patient for whom living is a constant struggle, and one without a foreseeable end.

The suffering occasioned by a lack of a 'light at the end of the tunnel' carries with it a different burden from that of a life about to end, but is as heavy a burden nevertheless.

Bereavement may be of a somewhat different nature, but ongoing losses sap hope in just the same way, their intractability being in itself a major feature of the experience of unremitting chronic illness.

The National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) state in their Draft National Plan and Strategic Framework for Palliative Care (2000-2005),

"Palliative and supportive care differ in philosophy from curative strategies in focusing primarily on the consequences of a disease rather than its cause or specific cure. Our approaches are therefore necessarily holistic, pragmatic and multidisciplinary and there is practically no distinction between palliation and support."

O'Neill and Fallon (2) noted in their 1997 review:

"Palliative care is necessarily multidisciplinary. It is unrealistic to expect one profession or individual to have the skills to make the necessary assessment, institute the necessary interventions, and provide ongoing monitoring."

More recently, Mann, a nurse consultant in pain management at Poole Hospital in Dorset, published an article in the British Medical Journal, (3) in which she stated:

"If the principles of alternative therapists could be combined with the efficacy of a carefully assessed, evaluated, and flexible pharmacological regimen, much of the misery of pain could be reduced. Perhaps now is the time to accept the limitations of conventional medicine and a "one size fits all policy" and to embrace a comprehensive multidimensional approach to pain management."

The NCHSPCS stress that

"The first step is to make palliative care a national priority area and to ensure that this is identified as such in the National Priorities Guidance."

The organisation recommends:

"It is clear that whatever shape the National Plan for Palliative Care may take, there must be robust organisational arrangements at local level for implementing its recommendations."

In their document, they cite results from the 1999 Palliative Care Survey, which drew on information from 3 main sources:

- * The MDS national collection of data for 1998/99

- * A DOH survey of HA perceptions about palliative care provision

- * A DOH commissioned survey of home care and hospital support teams

The survey showed:

- * Service provision assessed on a regional basis reveals widely divergent service volumes in respect of all service components

- * The regional aggregate data disguise even greater divergence between Health Authority areas and in particular between providers

- * It is unlikely that the differing levels of provision reflect differing levels of need e.g. differences in the incidence of cancer deaths, in levels of social and economic deprivation

- * The evidence-based requirement for multi-professional teams to be available in all care settings has yet to be achieved

- * Out of hours access to specialist and primary care teams is deficient almost every where

- * Access to services is also widely divergent but does not always reflect the resources available i.e. some Regions with fewer resources appear to achieve greater access than other Regions with greater resources.

* The introduction of mapping catchment populations through post-codes for each service provider is essential

* One third of Health Authorities had not developed and published a palliative care strategy

* Patients with a non-cancer diagnosis are not gaining access according to need

In-patient Services

The average number of beds per million population located in each NHS Region varies from 34 in Trent up to 62 in North West and South East ,the overall average in England being 51. Access to beds varies from 547 new patients per million per year in the West Midlands up to 958 in the North West.

Day Care:

The estimated number of day care places located in each NHS Region available per year per million population varies from 7157 in London up to 16571 in Trent with an average in England as a whole, of 13198. Access varies from 274 new patients per million per year in South West up to 394 in North West.

Home Care:

The ratio of community nurse specialists in palliative care located in each NHS Region to million population varies from 15.31 in Trent up to 29.86 in South West i.e. a variation of 95%. The average in England is 20.56.

The ratio of doctors to population ranges from 7.9 doctor sessions up to 21.1.

Access to hospital support varies from 1393 new patients per million per year in Eastern up to 2575 in West Midlands with an average of 1944.

Around half of all community nurse specialists in palliative care work in teams with a doctor but only one third in teams with a social worker and only 20% in teams with physiotherapists. Only one quarter work in teams with a doctor and social worker.

The NCHSPCS conclude:

“Consequently the concept of a multi-professional specialist palliative care team has yet to become a reality in most parts of the country.”

More recent results from the organisation based on statistics from 2000-2001:

In-patient services

Total number of adult hospices and palliative care units

(27% of these are NHS managed) 208 (+ 25 for children only)

Total beds 3029 (+ 186 for children)

Beds per million population (adults) 51

Hospice size - average 15 beds (7 for children)

Most common size 10 beds

Estimated number of admissions per year 59 000

Estimated number of new admissions per year 41 000

Mean length of stay 13.5 days

Day Care

Number of palliative care day care units 243

Average number of places per service per day 14

Estimated number of attendances per week 9 000

Estimated number of patients cared for annually 32 500

Home Care:

Number of different palliative care nursing services of which over a third are based at hospice inpatient units 334

Estimated number of patients seen annually 135 000

Estimated new patients per year seen by home care nurses 95 000

LESS THAN 5% OF PATIENTS HAVE A NON-CANCER DIAGNOSIS. The NCHSPCS state:

"The percentage of patients gaining access to specialist palliative care services who have a non-cancer diagnosis is only 4.3% for both in-patient and home care whereas it could be expected that the percentage gaining access would be between 25 and 50% if access reflected need."

O'Neill and Fallon (1) cite the following statistics, based on data from St. Christopher's Hospice:

Service

No of units

Inpatient units 223

Beds 3253

Day care centres 234

Home care teams 408

Hospital support teams 139

Hospital support nurses 176

Help the Hospices use the following statistics on their website:

“In the UK 236 hospices provide a total of 3,279 beds for in-patient care. Of these, 25 services and 186 beds are for children.”

The NCHSPCS estimate that the total cost of current services is around ?300 million:

- * Between £165 and £180 million is funded from charitable sources

- * Between £120 and £135 million is funded by the NHS

For the financial year 1998/99:

- * An occupied bed day - £207.50

- * A day care attendance - £81

- * A home care visit - £60

It is estimated that the average cost per bed per year is around £58,000 and that the average cost of an episode of care is around £2,700.

The additional running costs for an extra 100 beds would therefore be about £6 million per year plus the initial capital costs.

Each day care place costs around £13,500 per year. The average number of attendance's per patient is unknown therefore the average cost per patient cannot be estimated. The additional running costs for an extra 100 day care places would be around £1,350,000 per year.

The National Council's survey on voluntary hospice funding for 1999/2000 led to the following estimates in respect of funding sources and expenditure on running costs for that year.

* Total running costs were £215 million, 10% more than in 1998/99.

* The NHS contributed £65 million i.e. 30% of running costs compared with 32% in 1998/99

* The NHS cash contribution was 3.8% more in 1999/2000 than in the previous year "but did not fully meet pay and other price inflation";

Intermediate Care

This is a concept included in the NCHSPCS document.

"Intermediate care is a whole system approach to a range of multidisciplinary, multi-agency services designed to promote independence by:

* Reducing avoidable hospital admissions to acute hospitals

* Facilitating timely discharge from acute hospital and promoting effective rehabilitation

* Minimising premature or avoidable dependence on long term care in institutional settings

In effect, the proposed Community Pain Treatment Team would constitute a facility of Intermediate care.

PALLIATIVE CARE RESOURCES

The CSAG report (4) noted:

“Specialist palliative care services are usually better organised, with clearer policies and better funding than those for chronic non-cancer pain”

For instance, St. Ann's Hospice in Greater Manchester runs the following services:

- Supportive outpatient care includes a range of clinics to support patient and family/carer both physically and psychologically.
- Community services: team of nurses and doctors providing 'respite-at-home services' working in partnership with Primary Care Teams. Specialist Community Team comprises Consultant, SW and Macmillan Nurses. Access by self-referral or professional referral by GP, District Nurse, Specialist Nurse or other professional.

The Scottish partnership for Palliative Care (S P A) contributes to national policy, guidelines and standards and underpins improvements at a local level by means of professional support and networking.

The November 2001 10th. Anniversary SPA Conference, which had the overall theme

"Palliative Care for All- Responding to Need not Diagnosis",,

highlighted

"the unmet needs of people with a range of non-malignant conditions";

Key themes included the

"common need for pain and symptom management across a range of diseases";

This demonstrates that there is a strong need for a patient-centred approach rather than a diagnosis-oriented approach.

The Scottish Partnership for Palliative Care (SPPC) is the national umbrella and representative body for palliative care in

Scotland, being an independent body with charitable status set up in 1991

to promote the extension and improvement of palliative care services in

Scotland, whether provided by voluntary organisations or by the NHS.

The Clinical Standards Board for Scotland (5) has published a Clinical Standards for Specialist Palliative Care document.(6) in which the following statement is a recurring theme: standards need to ensure that:

"Specialist palliative care services can be accessed according to need."

The document also recommends:

"Specialist palliative care is made available to patients and their carers through a range of integrated service components and facilities, designed to respond to varied individual needs. A variety of models of care may have a contribution for different purposes, or for patients at different stages of the disease process."

And:

"All patients with progressive incurable disease have access to specialist palliative care services which address pro-actively all the symptoms of their condition and the effect these symptoms have on them and their family/carers.

Patients with complex palliative care needs require a wide range of therapeutic interventions for symptom control.

The relevant specialist palliative care services must have access to the necessary level of trained staff to safely manage these interventions."

More specifically, the Board notes the following needs:

"patients are actively involved as partners in symptom assessment and control; the changing pattern of pain and other symptoms is anticipated; a variety of methods are used to assess pain and other symptoms; a plan of symptom management is devised to include pharmacological and nonpharmacological approaches" as well as,

"wide range of modalities of treatment are available for symptom management."

With regard to psychological needs:

"ongoing support to assist patients and those important to them to address emotional issues, including those arising from the process of loss and change."

In particular, they recommend:

"Specialist services demonstrate that the needs of children as patients, and as relatives, have been recognised and met with services suitable to age and stage of development."

There is specific mention of non-malignant conditions, and an emphasis on living and the recommendation that:

"There is efficient and effective use of specialist resources in order to enable patients with complex needs to have access to the services according to identified need.

A short length of stay and a high proportion of discharges are two measures that demonstrate a focus on active management and rehabilitation.

The service must be able to support patients with non-malignant, progressive, degenerative diseases as well as those patients with cancer."

The Association of Children's Hospices has a website (7) on which they quote a mother, speaking about a children's hospice:

"above all, it is a place for living".

This ethos is a vital one.

The International Association for Hospice and Palliative Care (8) states the following as guidelines for Palliative care:

- "focus on the quality of life is the key feature of the definition
- it is person-oriented, not disease-oriented
- it is not primarily concerned with life prolongation (not with life shortening)
- it is not primarily concerned with producing long term disease remission
- it is holistic in approach and aims to address all the patient's problems, both physical and psychosocial
- it uses an interprofessional approach involving doctors, nurses and allied health personnel to cover all aspects of care
- it is dedicated to the quality of whatever life remains for the patient"

One can see that these issues do not preclude the provision of care for patients with non-terminal illness.

There is no doubt that resources for patients are as yet suboptimal and that to include non-terminally ill patients will further stretch them. However, there is a substantial level of need.

IAHPC cite the following:

"THE NEED FOR PALLIATIVE CARE

- fifty-two million people die each year

- it is estimated that tens of millions of people die with unrelieved suffering
- about five million people die of cancer each year, to which can be added the numbers of patients dying with AIDS and other diseases who might benefit from palliative care
- that many people die with unnecessary or untreated suffering has been well documented in many studies and published in hundreds of scientific papers and reports
- in developed and developing countries alike, people are living and dying
- in unrelieved pain
- with uncontrolled physical symptoms
- with unresolved psychosocial and spiritual problems
- in fear and loneliness
- this is the suffering that could be helped or prevented with palliative care
- the World Health Organisation (1990) and the Barcelona (1996) declarations both called for palliative care to be included in every country's health services

Note the inclusion of people living in unrelieved pain and with uncontrolled symptoms...this must include patients with non-terminal illness, and their protracted and prolonged suffering is surely no less important than that of people with cancer or other terminal illness.

CONCLUSION:

Chronic pain has a profound effect upon the lives of patients and their loved ones, regardless of the underlying cause.

Prolonged suffering in conditions where deterioration is slow and there is no significant shortening of life expectancy should be addressed as a part of Palliative care with as much vigour and attention as that given to life-threatening illnesses.

The principles of Palliative Care require that :

“The ultimate goal in planning a palliative care service is for patients to receive optimal palliative care wherever they are (in hospital, hospice or at home), and care which continues in a seamless manner when they are moved between places of care” (IAHPC 8)

To this end, for patients with non-terminal chronic illness, a service which provides a combination of community-based care (ongoing) and in-patient, hospice type care (intermittent, respite) is likely to be of optimum benefit.

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[1] <http://www.helpthehospices.org.uk/hospicecare/index.asp>

2 O'Neill W, Fallon M BMJ 1997;315:801-804 ABC of palliative care: Principles of palliative care and pain control

3 Mann E BMJ 2003 Jun;326:1320-1321 Managing pain

4 Clinical Standards Advisory Group (Commission for Health Improvement) Report, 2000

5 www.clinicalstandards.org

6 <http://www.palliativecarescotland.org.uk/publications/palliative.pdf>

[7] <http://www.childhospice.org.uk/typical%20hospice.htm>

[8] <http://www.hospicecare.com/manual/IAHPC2.htm>