

# **Palliative Medicine: an Emerging Discipline**

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## **Introduction**

Despite the advent of Gene therapy, some fundamental facts of life remain the same. Science has managed to increase a sample person's average life but death remains the only sure event in life. However, accepting the terminal and incurable nature of certain diseases has been difficult and as the doctors develop more cures, the dying becomes failure and is ignored, not only by the scientists, but also the public. Even in 12th century, patients with incurable diseases flocked to St Bartholomew's Hospital, London with great expectations as they heard the stories of remarkable cures<sup>1</sup>. In this environment, providing quality palliative care has been a problem area.

The Concept of Palliative care is not new. History traces hospices as back as in 4th century. A Roman matron, Fabiola, opened her home for the hungry, sick-and dying people as "Christian works of mercy" after seeing earlier Syrian hospices<sup>2</sup>. In 20th century, hospices have developed enormously with the developments in pain control, symptom management, holistic care and bereavement counseling. St. Christopher's Hospice was established in London in 1967. It not only served as the example for high-quality care for the dying, but also served as the wellspring for a much wider movement capable of crossing national borders<sup>3</sup>. In 1974, USA had their first palliative care set-up with the advent of a Hospice at home team in Newhaven, Connecticut<sup>2</sup>. Since then, Hospice movement has rapidly spread all over the world. Being the pioneer, United Kingdom is still working hard to provide palliative care for all. Currently in UK, there are 219 in-patient hospices with 355 home care teams<sup>4</sup>.

Hospices were traditionally the places where patients went in to die with cancer. Over the last 30 years, this trend has been changing. Now the hospices provide care for not only the terminal care, but also specialize in symptom control, respite and rehabilitation. WHO has defined Palliative care as. 'the active total care of the patients whose disease is not responsive to curative treatment. Control of pain and other symptoms and of psychological, social and spiritual problems are paramount. The goal of palliative care is achievement of best quality of life for patients and their families<sup>5</sup>. More recently, the hospices have also been looking after the patients with Motor Neurone Disease, AIDS and end-stage organ failures

### **What do the hospices Palliative Care Units do?**

The patients are referred to the palliative care teams, most overwhelmingly, for the purpose of Symptom management. Since Twycross found the advantages of oral Morphine and parenteral Diamorphine for Cancer pain in 1977, these are accepted as the drugs of choice through the mentioned route<sup>6</sup>. Over the years, we have seen advent of newer opioids like Methadone, Hydromorphone, Oxycodone and Fentanyl, etc. There has also been a lot of work done in the fields of types of pain e.g.. bony. Neuropathic, muscular visceral etc. Unfortunately, the side-effect profile of these drugs remains high.

Constipation has been the most troublesome of these and it often acts as the barrier for the use of Morphine with non-specialized physicians treating cancer<sup>7</sup>. For this precise reason, palliative care teams, who are more used to these drugs, may provide valuable support. Same applies to the other symptoms control such as nausea, bowel disturbances, breathlessness, terminal agitation and confusion. These teams also often provide useful advice for the management of seemingly minor symptoms that may pose a major problem to some patients such as night sweats, itching, hiccups etc.

Other areas where palliative care teams provide invaluable services are the psychological, emotional and spiritual support. Patients with terminal diseases have enormous needs and looking after them may cause extraordinary physical and emotional strain on relatives<sup>8</sup> as well as practical hardships<sup>9</sup>, which in turn may also increase psychological strain. All the professional carers in palliative care set-up are trained to be well aware of it and that is why; they concentrate on providing the psychological support. In fact, Palliative care teams are now perceived as either 'pain control experts' or 'someone to talk to'<sup>10</sup>.

Traditionally, a palliative care unit or hospice has doctors, nurses, occupational therapists, physiotherapists, religious scholars, social workers, counsellors, volunteers and educationists. This list in itself explains the diversity of services they provide tailored according to the local needs and resources.

### **Palliative Care in Pakistan?**

A recent paper suggested that there are no hospices in Pakistan<sup>11</sup>. That is true in its sense of modern day hospice. However, there is one hospice each in Rawalpindi and Karachi. These may not be well up to the standards of a modern hospice but their existence does explain the need of the hospice culture. We acknowledge that the concern about the distress of dying alone at home due to unavailability of relatives and friends is not the same as in west<sup>12</sup> as this is replaced by the strong family network. This also represents the Pakistani majority population's belief in religion, as they believe in, 'Your Lord has decreed that you worship none but Him, and that you be kind to parents. Whether one or both of them attain old age in the life, say not to them a word of contempt, nor repel them, but address them in terms of honour. And out of kindness, lower to them the wing of humility, and say: My Lord, bestow on them Thy mercy as they cherished me in (my) childhood<sup>13</sup>'. However, it is not contradictive to urge of seeking remedy and help, as the Holy Prophet (SAW) said to his companions, 'Take medicine as Allah has not created a disease without creating a cure except for one i.e.. old age<sup>14</sup>'.

Recently, a study in Saudi Arabia assessed the needs for palliative care and concluded that there is need for initiating the provision of palliative care services in the Saudi health system<sup>15</sup>. India has already started training programmes in Palliative care along side running palliative care units. Among the Medical professionals in Pakistan, there is unfortunately the prevalence of the phrases like.

'There is nothing more we can do!' which in itself is not a true statement<sup>16</sup>. It has been acknowledged time and again that the environment in specialist palliative care units differs from that in acute hospital settings where recognizing and addressing problems may be difficult because of frustrations, lack of education, confidence and time<sup>17</sup>.

Healthcare profession is about improving the quality of life. Death and dying are not a failure but the most natural things in life. There is always something one can offer, whether it is palliation of physical or emotional problems, a sensitive ear for spiritual issues, or our communication skills to help the patient and family<sup>16</sup>.

There are services available for acute cancer care in Pakistan but unfortunately, there is a great hiatus between diagnosing incurable and dying. which remains the responsibility of the healthcare profession. We recognize that resources, culture, litigation (e.g. regarding Morphine availability) are big obstacles but none of these is different from the ones faced at the beginning of any other science. People in palliative care are well known for their lateral thinking and the use of drugs and means not known to the healthcare profession in the past. Use of drugs for unlicensed use and its success is a tale in itself<sup>18</sup>. Medicine or healthcare is not only to provide cure but also to offer comfort and empathy. By denying the terminally ill patients of the symptom control and psychological support, we, as healthcare professionals, are not fulfilling our duty.

We believe that there is urgent need and definite scope for palliative care services in Pakistan. It is still an emerging field even in developed countries, but denying the symptom control, distress relief and support to the dying and their loved ones should no more be a routine and acceptable practice in our society. We, the doctors and other healthcare professionals, are more responsible than others in taking all measures possible to see Palliative Medicine emerging on the horizons of Medicine in Pakistan. To achieve, 'total care of the patients whose disease is not responsive to curative treatment'.

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