Palliative Care: End of Life Care

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'Death be not proud, though some have called thee Mighty and dreadful, for thou art not so.' (Holy Sonnets X, J Donne)

At present some 50 million people die yearly, and yet the care available for those who leave life falls far short of those who enter it (1). Cancer, in particular, is a major public health problem worldwide. There are 10 million new cases of cancer and six million deaths annually from this non-communicable disease (2). Twenty years from now the global burden of cancer will double. The World Health Organization (WHO) Programme on Cancer Control has estimated that by the year 2020, approximately 70% of the annual 20 million new cancer cases will occur in developing countries (2), where as many as 80% of patients are diagnosed when the disease is already in its late stages. Palliative care and pain relief will be the only realistic treatment options available to these patients.

What then is palliative care? It is tempting to think of palliative care as something new, when in fact it is as old as medicine itself. Long before doctors ever realistically dreamed of curing their patients, they saw their task as the relief of suffering (3).

Suffering may be defined as the distress associated with events that threaten the intactness or wholeness of the person, a whole person, not just a body or a mind. Most people facing a terminal illness will undergo some degree of suffering, and it may manifest in many different ways; their loved ones will undoubtedly be suffering too. The WHO has defined 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 the achievement of the best quality of life for patients and their families'. It goes on to state that palliative care 'affirms life and regards dying as a normal process, it neither hastens nor postpones death, ... offers a support system to help patients live as actively as possible until death, ... and offers a support system to help the family cope during the patient's illness and in their own bereavement' (4).

The paper published in this issue of the Journal by Kreitzschitz and Cox Macpherson (5) does much to highlight

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the fact that much needs to be done in the Caribbean region to develop and enhance palliative care provision for terminally ill patients. In the recorded interviews with patients and their caregivers, the suffering they experienced was highlighted. Poor and inadequate pain control, poor psychosocial support, and lack of information for families on what to expect and how to care for their loved ones once they became terminally ill were some of the concerns. Similarly, the healthcare professionals highlighted their own lack of education in this area and the need for national policy or guidelines regarding the care of these patients.

Globally, palliative care is a neglected area. The need today is enormous and is likely to increase dramatically in the near future (1). In the Caribbean region, we are no less in need than other developed and developing countries around the world. How then can we move forward? Resources worldwide for palliative care are limited, and a rational approach is essential. Even limited resources can have an impact provided that relevant priorities are set and strategies are implemented.

The implementation of a cancer pain relief programme can be used as a model for the further development of more comprehensive palliative care services. Pain is prevalent in cancer especially in the late stages, and between 80-100% of patients will have pain at some time during their disease trajectory. Tragically, cancer pain frequently goes untreated, and when it is treated, relief is often inadequate. There are many reasons why cancer pain is not adequately treated at present (5), including;

- * absence of national policies on pain relief and palliative care
- * lack of awareness on the part of healthcare workers, policymakers, administrators and the public that most cancer pain can be relieved
- * shortage of financial resources and limitations of healthcare delivery systems and personnel
- * concern that medical use of opioids will produce psychological dependence and drug abuse
- * legal restrictions on the use and availability of opioid analgesics.

To respond to these issues the WHO advocates a strategy with the following key components (6)

 national or state policies that support cancer pain relief through government endorsement of education and drug availability 266 End of Life Care

* educational programmes for the public, healthcare personnel and regulators,

* modification of laws and regulations to improve the availability of drugs, especially the opioid analgesics.

These foundation measures are important and proper implementation is unlikely if all three components are not established concurrently.

Healthcare professionals need to be made aware of the WHO protocol for treating cancer pain. This method of treatment, known as the WHO analgesic ladder, has been validated and is now the protocol of choice worldwide (6). This is a three step ladder with guidelines for managing mild to severe cancer pain. At step I, pain is managed initially with drugs like paracetamol and nonsteroidal anti-inflammatory drugs. When pain is not controlled at step I, step II is adopted which involves the addition of a weak opioid, such as codeine, to step I. If pain persists or increases, the patient is moved to step III when the weak opioid is replaced by a strong opioid such as morphine. As much as 90% of all cancer pain can be controlled by application of this relatively simple approach.

Kreitzschitz and Cox Macpherson point out that 'in the developed world, hospice care and palliative medicine are increasingly used to provide effective pain relief and support for dying patients and their families' (5). We in the Caribbean

need to embrace this type of healthcare provision as a matter of urgency. Models of palliative care provision differ around the world and can vary greatly between countries depending on socio-economic conditions and cultural issues (7). The English-speaking Caribbean is a relatively small region with similar socio-economic and cultural perspectives. Surely the time has come for us to work together on local, national and regional levels to help governments and health professionals develop the types of palliative and end of life care-services so desperately needed.

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