

Organization and development of pain clinics and palliative care in developing countries

How much would you spend to keep yourself pain free, when afflicted with chronic intractable pain or terminal cancer-related pain and you happen to be a resident of a developing country with a low per capita income? Maybe an amount equivalent to US \$5000 or \$10 000? This sounds ridiculous! But is it? In other words what value would you put on your quality of life? How much funding would be required to set up an ideal pain clinic in a developing country? If these questions sound ridiculous, think again. A brutal reality awaits many of us.

In 1961, John J. Bonica, along with Lowell White, established the first pain clinic at the University of Washington, Seattle. Their efforts were so well organized and their multidisciplinary treatment so successful that this clinic has since become a model for numerous other pain centres all over the world. Since then many pain clinics have been established in the western world. But what about the developing nations? They also need a network of pain clinic infrastructure to manage what is a vast population of chronic pain and cancer pain patients. But in developing countries the realities are very different and the situation is grim and frightening. Certainly a depressing scenario, yes, but is anything new in this? Unfortunately, no. Our great grandparents would have faced a similar situation. It is just that the global developments in pain management practice over the years have made the scenario more probable now.

In the context of the developing nations, consider the fact that you are likely to live longer than your parents or grandparents. An average Indian used to live for barely 40 yr in 1947 but by 2016 that same person would be expected to live for about 68 or 70 yr. As healthcare costs have been escalating rapidly, one can imagine the healthcare costs, related to optimum pain management of age-related ailments in developing countries to be enormous and beyond the reach of the common man.

Special problems in organizing pain clinics in developing countries

In developing countries, the concept of pain clinics has still not reached the pivotal point of acceptance by the medical community nor by the many other individuals who come into contact with pain patients. An ideal pain clinic, as of today, is difficult to achieve in the kind of set-up existing in developing countries. We in developing countries face specific problems while organizing a pain clinic.

The problem of conceptual acceptance of pain clinics

This idea has not even reached the minds of many medical experts. The concept that chronic pain and cancer pain should be dealt as separate entities and managed in a centralized multidisciplinary fashion has not yet been accepted.

The problem of space

Space is at a premium and finding space for a new pain clinic service within existing overstretched outpatient services can be quite difficult. This should not, however, be the reason for failing to organize a pain clinic service in a referral hospital and medical institution.

The paucity of funding

In a system with limited and inadequate resources, the pain clinic tends to be low in the list of priorities when compared to many other specialties.

The lack of health insurance facilities in developing countries

At present not even 1% of the population in this part of the world is covered by health insurance. Hence it is quite possible that any pain management-related healthcare expenses could wipe out the entire accumulated family wealth.

The problem of getting the right equipment given the paucity of funds

This applies especially in the context of interventional pain management equipments like an image

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intensifier, a spinal cord stimulator, programmable and implantable intrathecal pumps, and radio frequency thermo-coagulation equipment and probes. It might even prevent the purchase of basic simple equipment.

There is no definitive teaching and training programme regarding pain clinics in developing countries

Chronic pain management is not even mentioned in the undergraduate and post graduate curriculum of medical education in these countries. Hence developing the speciality of chronic pain management is very difficult. There is also a lack of motivated and dedicated people to work in the pain clinics.

In view of the above-mentioned factors, there is presently minimal original research on pain management in developing countries. With the help of the limited infrastructure, we do have to our credit some of the most original work on brain stem auditory evoked responses and somatosensory evoked potential changes following electro-acupuncture therapy in chronic pain patients referred to the pain clinic [1,2]. We have also evaluated P 300-event-related potential (cognitive profile) changes following epidural methylprednisolone administration in patients with chronic low back pain [3,4]. Recently, there have been a few case report publications from pain clinics in India [5,6]. Also a World Health Organization collaborating centre in South India has published an article on improving access to opioid analgesics for palliative care in India [7].

Pain management clinics in India

While currently there are 3100 pain management clinics listed on www.pain.com, the number of pain management clinics in India would be around 15 or so, including the one at our own medical institution. It is quite a sobering thought that this tiny number of pain clinics is all that is available for the second most populous nation on earth. There are many problems in setting up a pain clinic in India. It is certain, however, that there exists a vision for many more pain clinics to be set up in India in the near future, despite the above-mentioned problems encountered in the planning.

Monitoring performance of pain clinics

In the west, pain clinic treatments are continually evaluated [8], despite their difficulty being managed by a multimodal approach. For monitoring the performance of pain clinics and fulfilling the essential requirements of clinical governance, Griffiths and colleagues have recently, successfully developed a computer-based system, the Pain Audit Collection

System, for outcome evaluation of the multiple, complex interventions adopted in pain clinics [9]. It is evident that a high quality clinical database is mandatory for measuring the outcome in pain clinics and this is one vital area where the developing nations are lagging behind as they have hardly any databases to track interventions in the pain clinics. In developing nations there is no dearth of willingness or inclination to employ these databases but the commitment and assistance of the government department of health and finance, and the private hospital trust is required.

Challenges in organizing palliative home care in developing countries

Slightly more than one million people in India suffer from cancer pain every year [10]. As in many other developing countries, cancer tends to be diagnosed in the terminal stages when pain is dominant and often severe [11]. Worldwide, at least four million people suffer from cancer pain everyday [12]. Many of these individuals do not obtain pain relief [13,14] despite the established efficacy of the World Health Organization's three-step ladder approach for cancer pain relief in about 90% of cancer patients [15]. It is surprising that morphine is manufactured in India and yet is not available to most of the inhabitants of India who need it. According to Joranson and colleagues [7], therapeutic morphine consumption during the period 1985–1997 decreased by 97%, reaching a low of 18 kg in 1997. It is incredible that in 1997 India's per capita therapeutic consumption of morphine ranked among the lowest in the world (113th of 131 countries) [16]. Rajagopal observed that much of the supply of morphine for the rest of the world comes from cultivation of poppies in three Indian states [17], yet only a trickle reached India's domestic market.

Palliative care experts including Dame Cicely Saunders and various World Health Organization specialists have educated health professionals in the Indian sub-continent. Their efforts led to the establishment of the first palliative care centre, 'Shanti Avedna Ashram' in 1986. Subsequently in 1992, pain relief and the availability of morphine were specified as priorities in the National Cancer Control Program of India. Although the Ministry of Health and Family Welfare of the Government of India has specified that oral morphine should be made easily available for the relief of severe cancer pain [18], there have been many difficulties in its supply even to the medical institutions and tertiary government hospitals in India.

In a bid to draw international attention to the most unfortunate situation unfolding in India, the International Narcotics Control Board, which monitors the adherence of national governments to international

drug treaties and to the availability of narcotic drugs (both legal and illegal), asked the Government of India to take effective measures to ensure the adequate availability of oral morphine for cancer pain relief [19].

Care of the dying has been a constant concern of human society throughout history [20]. This is highly significant in view of the fact that although cancer is often regarded as a problem of the developed world, even now more than half of the cancers occur among the three-quarters of the world's people who reside in the developing nations. The burden of cancer will increase in the very near future due to an increase in the extent of population exposure to tobacco and an increase in the proportion of the elderly in most countries [21].

In the developing nations, there has been a constant decline of palliative care from the norm of medical practice to a marginalized field. Those who are dying are given the lowest medical priority. Historically there is evidence that in India, the Emperor Asoka (AD 238) established a refuge for the dying in Varanasi near the sacred Ganges river. Patients would come there to die, knowing that their ashes would be thrown in the sacred river to help their souls reach *moksha*, or liberation from the eternal cycle of death, rebirth and reincarnation. In India, today there are *mukti-bhavans* to which are brought the suffering patients who have stopped eating or drinking [22]. Most die within the first week, all within another week or so. Priests attend not to cater for medical needs but only spiritual needs. Small portions of *tulsi*, a sacred plant, are prepared and offered to the dying along with the water of the Ganges. Death comes in a natural, predictable and respectful fashion, and with detachment, dignity and little pain or suffering. Even in the New Testament (Matthew 25 : 35) there is a mention of 'Xenochodium', 'a place to receive the stranger', 'xenos'. Even today the concept of hospices is that these are places that offer physical care as a means to a spiritual objective.

In India, there has been a trend to resort to neurolytic nerve and plexus blocks for cancer pain relief, as it proves to be cost-effective in the long run. But the availability of an image intensifier and operating theatre exclusively reserved for neurolytic blocks is still a distant dream for the pain clinicians working in developing nations. At the same time there is no dearth of skills and talent for performing neurolytic blocks in these developing nations.

Recently it has been observed that the unfortunate downward trend of morphine consumption in India has been arrested due to the coordinated efforts of state, national and international initiatives. This reflects improvement in the palliative care programmes of only one state in India, i.e. Kerala. Kerala is a small state in the south west coast of India. It has only

1.2% of the area of India, yet it accounts for 3.1% of the country's population, making it one of the most densely populated states in the country. However, opioid availability has not improved in many of the states in India, where the rules have been amended but the policy changes have not been implemented. As a result, the palliative care programmes of even the medical institutions of the capital of India (New Delhi) have yet to obtain the oral morphine that they need.

Various states in India have no structured social security system, hence when pathology strikes a breadwinner, it destroys families. All these efforts have to be coupled with improving the education for healthcare professionals, administrators, politicians and the public.

The million dollar question is, why in developing nations, is cancer pain so poorly managed despite the availability of effective treatments? And how long will it take to improve access to opioid analgesics for cancer pain relief in India? The concept of quality of life (though essential for assessing the efficacy of palliative care programmes) seems to be a distant low priority thinking in developing nations. Despite these constraints the quality of life should certainly improve in cancer pain patients. Is it possible without the active involvement from the government? Probably the answer lies in acknowledging the limitations of both the government machinery and the non-governmental associations and going ahead with a plan of action involving both.

Conclusions

The only difference worth mentioning between a functioning society and a dysfunctional one is that the basic requirements of the people are provided – if not provided for – by the state. However, much of the gap may be between developed and developing nations; a country is expected to protect its citizens' fundamental rights for alleviation of both chronic pain and cancer pain and a definite concern for quality of life, even if millions of people in developing nations are unable to opt for private medical care. It is certainly possible to affect positive changes with a renewed hope. Our society is extremely optimistic that, even if there is a long way to go, the day is not far off when pain clinics and palliative care programmes in developing nations like India, will become an essential and integral part of the healthcare system that focuses on efficient delivery with reduced costs.

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