The Two Worlds of Palliative Care: Bridging the Gap with Nepal

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ABSTRACT

Despite past geo-political turbulence, Nepal has made significant progress in societal and economic initiatives, particularly in relation to social determinants of health. These improvements, however, belie the suffering of those with life-limiting disease due to pain, stigma, social and financial distress, consequent upon low patient, caregiver and health professional awareness of the need for, and availability of, appropriate care and support. Two Worlds Cancer Collaboration (INCTR-Canada) has been working with partners in Nepal to build capacity for palliative care by: (a) organizational and administrative support – establishing the Nepal Association of Palliative Care (NAPCare), and the creation of the Nepal Strategy for Palliative Care, approved by government in 2017; (b) "twinning" between 2 hospital palliative care units in Nepal and the Nanaimo Hospice and Victoria Hospice, BC, Canada; (c) sustainable growth of palliative care according to WHO foundational measures, implementing facility-based clinical programs, and home-based care aligned with the cultural, social, and economic environment of Nepal; (d) training of health professionals in adult and paediatricpalliative carethrough interactive on-line "distance learning" (Extension of Community Healthcare Outcomes, ECHO); (e) leveraging palliative care training and expertise across the government health system, and (f) local and international support to build a newfacility for Hospice Nepal to provide more support for more patients in a rural ambience on the outskirts of Kathmandu. Palliative care needs to become standard-of-care, providing peace, comfort and dignity for adults and children. Working collaboratively with partners in Nepal, the collective vision is a capable professional Nepali community leading palliative care services for all in need, wherever in need.

Keywords: Capacity building, Medical education, Two worlds Cancer Collaboration (INCTR-Canada, South Asia, telemedicine, Nepal)

1. INTRODUCTION

A cancer diagnosis in Nepal is really no different than anywhere else in the world. It is the ability to control cancer that differs, largely a consequence of context and circumstance - differences in standard of living, education, health literacy, social circumstances, behaviours, and timely access to, and availability of, appropriate care, treatment and support.

Globally, Nepal has one of the ten least urbanized populations, but it is also one of the fastest-urbanizing. Nominal GDP per capita is around US$ 1000. Overall literacy is around 70% and life expectancy at birth is approximately 70 years, a decade less than in Canada (Wikipedia contributors 2022). Two-thirds of all deaths are due to non-communicable diseases - chronic, primarily non-infectious diseases, commonly associated with life situations, circumstances and behaviours.

More than 70% of adults and 80% of children with cancer in Nepal will die of their cancer, compared with 45% and <20%, respectively in Canada (GBD 2017 Childhood Cancer Collaborators). These statistics, however, belie the suffering of those with life-limiting disease in Nepal due to uncertainty, pain, stigma, isolation and social and financial distress. The impetus for the development of palliative care in Nepal recognizes this profound and unmet public health need for the symptomatic care of people living with cancer and other life-limiting diseases.

Despite challenges in health and social circumstances there have been rapid and dramatic improvements to health care in Nepal. Health professionals strive to deliver high quality care, which, combined with the government's approval of a national strategic plan for palliative care, and a supportive global community of experts, will support knowledge transfer and capacity-building to achieve health expectations for Nepal.

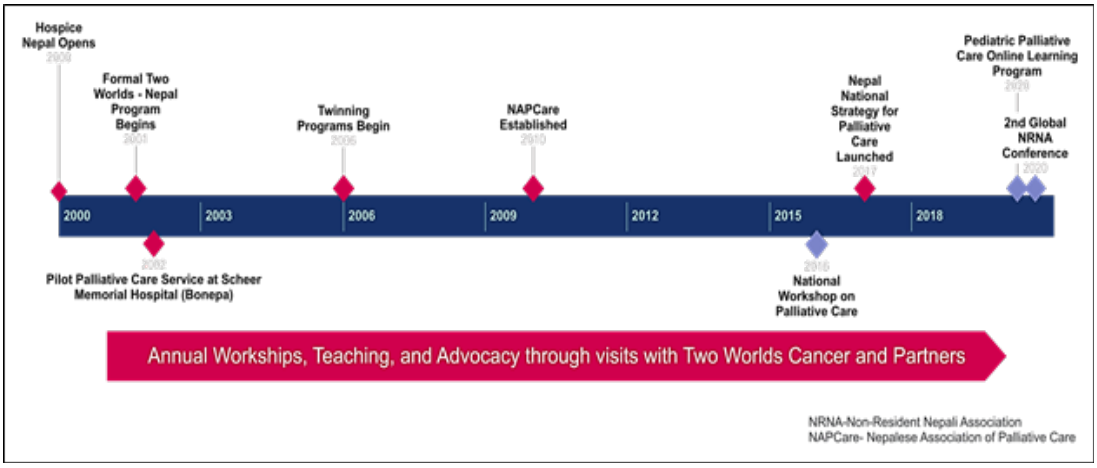

Fig. 1. Timeline of activities leading to the palliative care program in relation to important events in the recent history of Nepal

2. TWO WORLDS CANCER COLLABORATION

Two Worlds Cancer Collaboration (INCTR-Canada) is helping to build capacity for palliative and end-of-life care through collaboration with health professionals, sharing of knowledge through teaching, pain management, hospice care and care at home in the community. Two Worlds Cancer Collaboration is a volunteer-based, registered Canadian non-profit society and charitable foundation. The core of Two Worlds Cancer program is centred in Hyderabad, India, and from this site, collaborations in adult and pediatric palliative care extend across India, Nepal, Sri Lanka and Bangladesh. Community engagement has led to further initiatives in cancer control, particularly for high-impact cancers e.g. oral cavity cancer screening and early detection.

3. PALLIATIVE CARE DEVELOPMENT IN NEPAL

3.1 Twinning Programs With Bharatpur and Bhaktapur Hospitals

The Two Worlds Cancer Collaboration relationship with Nepal commenced with two twinning programs with hospices in British Columbia, Canada, established in the early 2000s (Brown *et al.* 2007). Fig. 1. Nanaimo Hospice, British Columbia was twinned with Bhaktapur Cancer Care Hospital, Bhaktapur and Victoria Hospice, British Columbia was partnered with BP Koirala Memorial Hospital, Chitwan, Nepal. The concept of twinning involves the establishment of a formal relationship between two organizations who offer similar programs and share common goals and interests. Each organization benefits from this partnership, shares friendship, encouragement and shares resources, and learns from each other's experiences and cultures.

At the Hospice Palliative Care Association Conference in British Columbia, Canada, in 2002, Dr. Stephen Lewis, Canadian diplomat and former UN Special Envoy for HIV/AIDS in Africa, encouraged hospices to develop twinning partnerships as an effective way to reach out to the developing world and strengthen the hospice palliative care movement worldwide. Key principles of twinning include patience and flexibility, sensitivity and humility, sustainability, and reciprocity. As part of these twinning partnerships, Two Worlds Cancer Collaboration physicians and nurses have made annual site visits to Nepal to work alongside their local palliative care colleagues to build capacity for sustainable palliative care programs. Activities of the twinning partnerships includetraining, education, workshops, nursing staff salary support, and support for medicines, including morphine (Canada H.Archived 2009).

3.2 Overview of Palliative Care in Nepal

Palliative care and support should be available for all individuals who need it, when they need it and where they need it. Universally, the majority of seriously ill individuals express a wish to die at home in the company of family, friends and loved ones. Although awareness of the need for palliative care is growing, the capacity to respond, in terms of scale, personnel, infrastructure, facilities, distribution of services and funding is still very limited in Nepal.

Palliative and end of life care is an essential component of cancer programmes (WHO/Cancer Control: Palliative Care 2018). The majority of patients will require end of-life support, currently provided for too few. This reflects a lack of awareness of the need and priority for palliative care. There are too few palliative care professionals (MDs, nurses, pharmacists, social workers, community health workers) and an insufficient number of trainees to recruit and build the work-force. There are additional challenges of retaining those who are trained.

Currently there are specialized palliative care clinical services available in Kathmandu and Bhaktapur Districts. Elsewhere, basic palliative care services are provided in private hospitals, a few district public hospitals, and a few community hospices, but these are often only accessible by long journeys over challenging terrain. A new Hospice (Green Pastures), supported by the Edinburgh Missionary Society and the UK government, has recently been established in Pokhara, Kaski District, in western Nepal.Few physicians or cancer specialists have dedicated training and expertise in adult palliative and end of life care and even fewer in children's palliative care.

To reach a dispersed, rural population, a decentralization of palliative care services is required, with establishment of expertise at the community, district, tertiary hospital and hospice levels. Several excellent examples of such programs exist in South Asia (Kumar 2007; Zaman *et al.* 2017). In Telangana, India, the Hyderabad Centre for Palliative Care has developed, and supports, palliative care activities in 31 community clinics across the state, with support and funding from the Telangana state government. In the past three years, a similar initiative has been developed by the Makawanpur Community Health Project in Nepal, which includes a rural palliative care program piloted by Hospice Nepal and Patan Academy of Health Sciences, supported by Two Worlds Cancer Collaboration and other grants.

Although oral morphine is available and is the single most useful medication for cancer pain control, there is limited familiarity with appropriate medical use of morphine and other opioids. Similarly, specialized symptom control that is often required at the end of life requires particular training and support which is not readily available for health care professionals working within the Nepali health system.

3.3 Governance

Those with expertise have established the Nepalese Association of Palliative Care (NAPCare), and with the help of Two Worlds Cancer Collaboration and other partners, are implementing a government-endorsed national palliative care strategic plan. NAPCare has focusedon developing a sustainable model of palliative care, guided largely by the World Health Organization's (WHO) foundational measures. NAPCare are advocates for and support, the implementation of facility-based clinical programs, and home-based care aligned with the cultural, social, and economic environment of Nepal. The organization is committed to working in collaboration with the government to build capacity, sustainability, and the inclusion of palliative care in national policy and programs.

3.4 Hospice Nepal

Hospice Nepal was the first free-standing palliative care facility in Nepal. The current facility is in an older building in Lagankhel, Lalitpur (Kathmandu Valley), but plans are underway with local and international support (Rotary, Fairfield, New Zealand and Challenge Fund, UK) to build a new, larger facility, providing more support for more patients in a calmer rural ambience on the outskirts of the city.

This new facility is also envisioned as a training hub for both post-graduate and under-graduate health professional education programs. The training hub will make use of Project ECHO (Extension of Community Healthcare Outcomes) and the established close relationship with the Ministry of Health, to expand access to palliative care training and expertise across the government health system.

Over many years and frequent visits, Two Worlds personnel have worked with, and supported the Hospice Nepal team in a range of educational and project development areas, partnering with the Hospice leaders as they have developed their vision for the expansion of palliative care services across the urban and rural settings of the country.

3.5 Palliative Care Education in Nepal

Currently, neither adult nor paediatric palliative care are recognized specialist medical disciplines in Nepal, and there are no specialist training programs for physicians wishing to specialize in this area.

In recent years, there has been a growing recognition of the role of online education platforms to disseminate specialized training in low-and middle-income countries (Frehywot *et al.* 2013). Using technology-enabled learning can address barriers of staff needing to take time off and travel to attend education programs, and the use of tele-mentoring interactive case discussions can further support the development of local competence and expertise (Bagayoko *et al.* 2014; Arora *et al.* 2017).

Over the past year, in partnership with local paediatric oncology programs, Two Worlds Cancer Collaboration has developed a paediatric palliative care ECHO program. ECHO is an international non-profit education movement, aimed at democratising specialist knowledge through building virtual communities of practice using a well-established and evidence-based methodology. ECHO follows a structured format to empower healthcare providers with new knowledge and skills through regular online teaching and mentoring sessions. The paediatric palliative care ECHO has received enthusiastic national support, with participation of 65 health care professionals across Nepal for the first 10-session program. A second paediatric palliative care ECHO course is now underway.

Training of health workers in Nepal by Two Worlds Cancer Collaboration has, to date, resulted in 16 nurses and 7 MDs undergoing training in Hyderabad, India, many continuing medical education seminars conducted in person in Nepal, and the development of a cadre of informed paediatric palliative care nurses and physicians through the paediatric palliative care ECHO program.

Nepali trainees have also attended Indian Association of Palliative Care conferences through Two Worlds Cancer support. In addition, the National Health Training Center of Ministry of Health in conjunction with the NAPCare has been conducting regular, one-week, hospital based palliative care training, involving actual patient care with safety procedures against COVID-19.

Standards of professional practice and accessible clinical care guidelines and support need to be in place to ensure a good standard of care irrespective of income level, or place of residence. An insufficiently developed knowledge, skills, research and expertise environment dis-incentivizes those health professionals who might otherwise consider palliative care as a career.

4. CURRENT AND FUTURE PLANS

Palliative and end-of-life care in Nepal needs to reach all those who need these supports. Palliative and end-of-life care is about people finding peace, comfort and dignity as they face a medically uncertain future, whether as adults, adolescents, children or babies.

Palliative care requires very little technology, equipment, or specialized treatments. An "essential package" of inexpensive and relatively simple interventions can deliver effective palliative care in a wide range of settings, even when resources are very limited (WHO 2018). Palliative care must also consider age, dependence, disability and life circumstance, to be adaptable to the specific needs of older persons, adults, adolescents, children, neonates, and their families. Health facilities, including hospitals and hospices, may be required for those who need supervised medical and supportive care.

Self-sufficient and sustainable palliative care for the population of Nepal ultimately requires incorporation of services, human resource and operating expenses into the government/ publicly -funded health care system. However, initiating and catalyzing the interventions required to achieve sustainable goals does not necessitate substantial initial investment by government. Thus, capital projects e.g. the new Hospice Nepal; for education, fellowship and mentoring programs; for internet-based ECHO seminar series, and for equipment, drugs and medical supplies, can be initiated and supported through philanthropy from both resident and non-resident Nepali community, by non-governmental organizations e.g. Two Worlds Cancer Collaboration, and by the private/business sector prior to assimilation of population-based palliative care into standard, accessible and affordable health care.

Improving palliative care is about educating, training and mentoring the needed health professionals. Developing recognised and suitable training programs adapted to the local healthcare environment, ensuring competence and expertise for physicians, nurses, allied health professionals and community health workers, and improving system-wide collaboration, communication and cooperation are important conditions for success (Imura *et al.* 2014)

5. CONCLUSION

Integrated population-based palliative care exists in many health systems around the world, in high income settings, but also in areas where resources are limited (Ddungu 2011). Palliative care is an affordable component of universal health care, which can decrease health care costs when practiced appropriately, by reducing unnecessary, inappropriate and ineffective use of acute health care and hospital services.

Building necessary capacity for adult and childhood palliative care in Nepal is achievable now, by developing the skilled health care leaders and workers in palliative and end-of-life care, building the necessary skills, knowledge, experience, expertise and collaboration in a way that develops local, proficient and sustainable capacity.

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