Addressing the need for palliative care in Nepal – the building of a hospice and palliative care education centre in Kathmandu

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Sandwiched between India and China and with a population of over 29 million people, a quarter of whom earn less than US$ 0.50 a day Nepal faces many challenges not least in healthcare. There is little palliative care provision for adults and children's palliative care is in the earliest stages of development. There is an urgent need for more hospice beds in Kathmandu as well as the expansion of the current palliative care outreach programmes into the rural regions of the country where 80% of the population reside. The number of trained palliative care health professionals is limited and key to the new hospice facility will be a state-of-the-art education facility.

Nepal is landlocked; located between India to the east, south and west and the Tibet Autonomous Region of China to the north. It has some of the most difficult terrain in the world, with 75% of the country being covered by mountains, meaning that access to the rural population to provide palliative care guidance and medication is extremely difficult.

Nepal has a population of over 29 million people with 60% of the population under 30 years of age. The average life expectancy has risen to 70 for men and 72 for women. The Ministry of Health is responsible for the support and administration of public health services including hospitals and clinics. The Nepalese government has approved a strategic plan for palliaitve care, but much work needs to be done to achieve the goals of this plan.

The burden of noncommunicable diseases is rising and patients with cardiovascular disease, cancer and respiratory conditions being most in need of palliative care *(1)*. Patients with cancer have a high burden of symptoms such as pain, breathlessness and nausea and vomiting. Two common cancers in Nepal: oral cavity cancer and cancer of the cervix are known to have particularly severe symptoms which are difficult to alleviate *(2)*.

Cancer incidence and survival rates in Nepal

Cancer incidence in Nepal is increasing and has become a major public health problem. It is now recognized that more attention should be paid to the need for palliative care - both in urban areas such as Kathmandu, but also among rural and remote communities. Lung cancer is the most common cancer among males followed by stomach, colorectal and oral cavity cancers. Among females, cervical cancer is the most common cancer followed by breast, lung and gallbladder cancers.

Comparing palliative care in Nepal and the United Kingdom

Dying in pain in Nepal is still a common occurance. In the United Kingdom when a disease such as cancer is beyond curative treatments, patients rightly expect at least to receive effective pain relief, and many will be offered comprehensive hospice care. However, in low- and middle-Income countries (LMICs), such as Nepal, the great majority of terminally ill patients have no access to pain relief medication and even less access to hospice care. As a result, many patients endure very painful deaths, causing both patients and their families immense suffering (Table 2).

Table 1: **Number of cervical cancer Incidences and deaths per Commonwealth region**

	Males	Females	Both genders
Population	13 348 435	15 788 373	29 136 808
Number of new cancer cases	8 943	11 565	20 508
Age-standardized incidence rate (world)	78.6	82.6	80.9
Risk of developing cancer before the age of 75 (%)	8.1	8.6	8.4
Number of cancer deaths	6 244	7 385	13 629
Age-standardized mortality rate (world)	56.1	53.9	54.8
Risk of dying from cancer before the age of 75 (%)	6.0	5.8	5.9
5-year prevalent cases	15 073	21 833	36 906
Top 5 most frequent cancers excluding non-melanoma skin cancer (ranked by cases)	Lung Stomach Colorectal Oral Cavity Thyroid	Cervix uteri Breast Lung Gallbladder Ovary	Lung Cervix uteri Breast Stomach Colorectal

Table 2: **Palliative care in the United Kingdom versus Nepal**

	United Kingdom	Nepal
Population	66,650,000	29,136.000
Those in receipt of palliative care in hospice each year	48,000	700
Those in receipt of palliative care at home each year	225,000	500
Number of adult hospice beds available	2,760	25
Total number of hospices	220	6
Number of dedicated children's hospices	58	0
Number of terminally ill patients with access to opioids	100%	9%

The Vision: Building a new Hospice Nepal and Palliative Care Education Centre in Kathmandu

Background:

Twenty years ago, four former Nepali schoolfriends got together and started the country's first hospice in Kathmandu. Today, from those very humble beginnings, Hospice Nepal has become an important centre for palliative care under the guidance of one of those four friends, Professor Rajesh Gongal, who is now the Vice-Chancellor of Patan Academy of Health Sciences (Figure 1). There is presently an 8 bed in-patient unit, a home based community programme in Kathmandu and a rural programme in the Makwanpur área (Table 3).

Figure 1: **Inside the existing hospice in Kathmandu**

The hospice is run as a non-profit, non-governmental organization (NGO) registered with the Social Welfare Council in Lainchaur, Kathmandu. It is a registered charity overseen by a Board of Trustees. All NGOs in Nepal have to get certification from the Social Welfare Council which is subject to an annual audit and verification by the Tax Division of the Finance Ministry.

Aims

With the current demand for palliative care in Nepal outstripping the capacity of the present services, there is an urgent need to expand Hospice Nepal and include facilities for the care of children. Eighty percent of Nepal's population live rurally where transport links to Kathmandu and other major centres are often difficult decreasing access to central services. The need to expand Hospice Nepal's current successful outreach programmes into more rural areas will thus be a major focus of the new hospice.

In particular, the provision for healthcare training and telementoring facilities are key to enable the leveraging of palliative care expertise across a wide population. It is planned to utilize the ECHO Programme which is a worldwide telementoring movement dedicated to the democratization of specialist knowledge which will enable clinicians to gain the expertise required to provide palliative care services and support (*4,5*). The ECHO network participants are able to learn new approaches for applying their knowledge across diverse cultural and geographical contexts (Figure 2). Patan University,

Table 3: **Number of annual admissions to current hospice services**

Year	In Patients	Kathmandu (urban community care)	Rural Community (in the Makwanpur area)
2017–2018	133	105	111
2018–2019	160	104	213
2019–2020	76	94	274

Figure 2: **The ECHO programme**

Two Worlds Cancer Collaboration Foundation (Canada) and the Hyderabad Centre for Palliative Care, India, have already successfully carried out ECHO programmes in adult and children's palliative care in Nepal. These organizations are partner organizations with Hospice Nepal.

Project Hospice Nepal

Those involved in the project come from Nepal, from across the globe and from a variety of backgrounds. Professor Max Watson and Dr Stuart Brown have been involved in various ways with Palliative Care development in Nepal and provide medical advice to the group, while there are other members from the commercial and voluntary sectors. There are ongoing fundraising campaigns in Nepal, the United Kingdom, New Zealand and Canada. The project was initiated by the Fairfield Rotary, Hamilton, New Zealand and in the United Kingdom, a registered charity, The Challenge Fund, has been actively campaigning to raise funds and to promote the project in order to attract as many supporters and donations as possible.

Fundraising has been slowed by the coronavirus pandemic – particularly in Nepal where the surges of Covid-19 have had a devastating impact across the country. However, whilst the pandemic has slowed the progress of fundraising, it has also highlighted even more starkly how important this project is to mitigate the suffering of thousands across the country who have died without access to palliative care support.

Phases of development

Phase 1: Land purchase

Plans for the construction of the new eco-friendly building have been drawn up and the land secured thanks to generous donations both from Nepal and overseas. Shortly before the onset of the pandemic, team members from the United Kingdom, New Zealand and Canada visited Nepal in order to view the site of the new hospice and to meet the Hospice board, the medical leadership and the project manager (Figures 4 and 5).

Phase 2: The build

The construction of the new building and associated areas will

Figure 4: **Visit to the site by Project Hopice Nepal team members in February 2020**

Figure 5: **The land purchased for the new hospice**

Figure 6: **Hospice 3-D image**

be overseen by Mr Om Rajbhandary, a well-respected Nepalese developer, and one of the original four friends involved with the creation of the current hospice. The quality of the building will be of the highest standard and meet stringent earthquake requirements, as laid down by the Government of Nepal who carry out regular inspections during the build. The building has been architecturally designed to be appropriate to Nepali culture and patient and family needs (Figure 6).

Phase 3: The fitting out

On completion of construction the fitting out phase will begin. It is envisaged that the new Hospice Nepal will consist of 25 beds with both individual rooms and small wards. There will be five dedicated paediatric beds with a play area for the children.

On the top floor there will be a "National Palliative Care Training Centre" where medical and nursing staff from across Nepal can receive training given by experts from Nepal and from other countries.

A lecture room and a small seminar room are planned along with IT facilities to enable tele-conferencing to support distance education and the ECHO networks.

Conclusion

Despite delays to the start of the project because of the devastating impact of the coronavirus in Nepal and around the world, pre-build work covering planning, detailed specifications, and tendering is underway.

The geographical diversity of the country will always pose a challenge, particularly with the coordination and delivery of palliative care into the more rural areas of the country. However, the new Hospice Nepal will provide increased access to care for adults and children both as in-patients and at home, becoming a state-of-the-art centre of excellence for the provision of palliative care, advocacy, and education. The unique collaboration between a proven committed team of palliative care pioneers, support from the Nepali Government and health service through the Palliative Care strategy, and the opportunity for collaboration with international supporters provides a strong platform for far reaching impact to improve the care of patients approaching the end of life across the country.

A new Hospice Nepal will be a central part of that development and it could serve as a blueprint for future collaborative initiatives both in Nepal and beyond. It is therefore vtal that this opportunity to build capacity in palltiative care for both adults and children progresses rapidly. ■

Further information on the project, together with details on all those involved, can be found on website www.projecthospicenepal.org.uk

Professor Max Watson is a Palliative Medicine Consultant in the United Kingdom and Director of Project ECHO at Hospice UK. He was formerly Medical Director of the Northern Ireland Hospice and Visiting Professor at the University of Ulster and Honorary Senior Lecturer at Queens University in Belfast. He is also Visiting Professor, Virtual Academy at St Margaret's Hospice in Taunton and Honorary Consultant at Princess Alice Hospice, Esher. Professor Watson worked in Nepal throughout the 1990s and has returned regularly to teach there. He has authored and edited numerous books including the "Oxford Handbook of Palliative Care" and the "Palliative Adult Network Guidelines (PANG) and has taught and lectured extensively across the world.

Dr Stuart Brown is a palliative care specialist at Waikato Hospital, New Zealand, where he is a Consultant in Palliative Medicine. He is a Rotarian and member of the Fairfield Rotary Club in Hamilton. Stuart has worked previously in Saudi Arabia in palliative medicine and later was Medical Director of the Tertiary Hospice and Palliative Care Unit at Abbotsford Regional Hospital in British Columbia, Canada. Since 2008, he has volunteered in Brazil, India, Nepal and Tanzania with the Palliative Access (PAX) Programme of the International Network for Cancer Treatment and Research (INCTR) and Two Worlds Cancer Collaboration, Canada.

Pat Newland is the Executive Director of the Challenge Fund, a UK registered charity, which fundraises for the treatment of cancer patients, particularly children, in low- and middle-income countries. Having gained a degree level qualification in modern languages, Pat has a background both in commerce and in politics having been a senior manager in the travel industry, served for 12 years as a Borough Councillor and is the owner and founder of a property business in London. She has always been active in the voluntary sector having been a school governor and a trustee of a number of charities including Druglink. She is a qualified radio presenter, producing and presenting current affairs programmes on local radio.

Professor Rajesh N Gongal is Vice Chancellor of the Patan Academy of Health Sciences (PAHS) in Kathmandu. He was the Founding Dean of the School of Medicine of PAHS. He is also the Founding President of Nepal Ambulance Service. He is the founding President of Hospice Nepal, the first palliative care centre in Nepal. He completed a fellowship in palliative care from Northern Ireland Hospice and Masters in palliative care from Ulster University. With colleagues, he has pioneered care teaching for doctors, nurses and rural healthcare workers across Nepal.

References

1. Swarbrick EM, Pietroni MA, Munday DM. "The Need for Palliative Care in Adults in Nepal: Projections Based on Modeling Mortality Data" *Indian J Palliat Care.* 2019 Jan-Mar;25(1):41-45. doi: 10.4103/IJPC.IJPC_177_18. PMID: 30820099; PMCID: PMC6388614.
2. Krakauer EL, Kane K, Kwete X, et al. "Essential Package of Palliative Care for Women With Cervical Cancer: Responding to the Suffering of a Highly Vulnerable Population" *JCO Glob Oncol.* 2021 Jun;7:873-885.
3. International Agency for Research in Cancer IARC - Nepal. https://gco.iarc.fr/today/data/factsheets/populations/524-nepal-fact-sheets.pdf Source: Globocan 2020
4. Arora S, Thornton K, Murata G, et al. - Outcomes of treatment for hepatitis C virus infection by primary care providers. *N Engl J Med.* 2011;364(23):2199-2207. doi:10.1056/NEJMoa1009370
5. .Komaromy, M., Ceballos, V., Zurawski, A. et al Extension for Community Healthcare Outcomes (ECHO): a new model for community health worker training and support. *J Public Health Pol* 39, 203–216 (2018). https://doi.org/10.1057/s41271-017-0114-8