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Strengthening childhood cancer services in Myanmar

Childhood cancer survival rates are now 75-80% in high income countries (HICs), but only 10-30% in low-middle income countries (LMICs), where 80% of children live [1]. This inequality relates to late or missed diagnosis, refusal or abandonment of treatment, lack of trained healthcare professionals and resources, excess toxic deaths and the perception of incurability [2-5]. Over 100,000 children die needlessly every year, most without any effective pain relief. At least 50% of childhood cancers can be cured by simple treatment. Cancer is increasingly life-threatening as the control of communicable diseases increases. An estimated 215,000 children of <15 years, and 85,000 adolescents of 15-19 years annually develop cancer worldwide [1].

World Child Cancer is a UK-based charity with the mission to improve diagnosis, treatment and support for children with cancer, and their families, in low-middle income countries [2]. The charity has supported programmes in 17 countries and has reached over 12,000 children since 2009. The concept is to facilitate long-term change through hospital twinning partnerships that can drive improvements in capacity and patient care.

In 2014, World Child Cancer established a partnership between Yangon Children's Hospital in Myanmar, Guy's & St Thomas' NHS Foundation Trust (London, UK), and The Dana Farber/Children's Hospital Boston (USA). The paediatric oncology unit in Yangon is led by Dr Aye Aye Khaing, who requested support to develop her unit, one of only two currently providing childhood cancer care in Myanmar.

Challenges in Myanmar

Myanmar has a population of over 54 million, with 33% under 18 years of age [6]. Up to 3,000 new cases of childhood cancer are expected annually, but only 250 cases were diagnosed at Yangon Children's Hospital in 2014. The main challenges being faced by people in charge of children with cancer in Myanmar are [7]:

- A lack of public and professional awareness of the early warning signs and symptoms of cancer, and how and where to seek help;
- Little or no specialist training for multi-disciplinary team members;
- A lack of reliable data collection to assess cancer burden and outcomes;
- Poor access to healthcare for the most vulnerable communities;
- Underdeveloped pathology services, leading to delayed or misdiagnosis;
- Inadequate hospital facilities;
- Huge financial burden on the family, who pay for some treatment, accommodation, travel, and suffer loss of income during long hospital stays;
- Limited psycho-social care for families and staff.

Myanmar's health budget per capita has increased from \$2 in 1999 to \$23 in 2014 [6]. Childhood cancer is not yet seen as a priority by the government.

While the government does provide some first-line chemotherapy and supportive medicines, families remain to some extent responsible for chemotherapy and antibiotics, and bear the full



Nurses from Children's Hospital Boston leading nurse training on the ward at Yangon Children's Hospital.



A patient and family members on the paediatric oncology ward at Yangon Children's Hospital.



A new nutritional support project has started for patients and families living on the haematology/oncology ward at Yangon Children's Hospital.

burden of travel and accommodation. The hospital has 36 beds for children with cancer, but it is nearly always full. The haematology ward adjacent to oncology also has 36 beds and shares the same staff, resulting in inadequate staffing for the overall workload. No family accommodation is available, making parents dependent on local charity or family connections for a place to stay, or they resort to sleeping in the hospital car-park with only minimal cover from the elements. Patients and siblings have no education or play therapy service. Parents suffer a huge loss of income during the months spent at the hospital. The one other centre at Mandalay Children's Hospital provides some treatment for children with cancer, but it does not have a trained paediatric oncologist and has only basic services for patients. Neither Yangon nor Mandalay Children's Hospitals have an integrated palliative care service, and both lack adequate analgesic supplies.

The one-year survival rate for children treated at Yangon Children's Hospital is <50%, although long-term survival rates are probably much lower (follow-up of patients remains a logistical challenge). Treatment abandonment rate is 25%, and is a higher rate for complex tumours (45-50%). Abandonment is most often due to financial constraints and family disruption.

Programme Plan

The World Child Cancer programme aims to contribute towards reduced child mortality through improved diagnosis, treatment and care for children with cancer. The programme plans are:

- 1) Development of the knowledge and skills of healthcare professionals;
- 2) Provision of treatment and support

services for children and their families;

- 3) Improved collection of statistical data on childhood cancer and the implementation of a reliable patient database;
- 4) Increased awareness amongst professionals and the public of the early warning signs/symptoms of childhood cancer and its potential curability. This includes advocacy aimed at the government to support paediatric oncology services.

This first phase focuses on building the capacity of Yangon Children's Hospital and ensuring that the infrastructure and staffing can cope with an increasing number of patients. Awareness promotion and accessibility improvements will focus on the most vulnerable members of society, especially those living at a distance from Yangon. Later stages of the programme will include how to support the development of Mandalay services and other satellite centres around the country.

Progress

Patient Support

As a result of this programme and support of internal donors the treatment cost burden for families has decreased. However, some drugs are no longer being funded by the Myanmar government, and the charity and in-country donors are trying to source funding for the deficit, to ensure that unaffordability is no longer a reason for abandonment. In 2015, a nutritional support project for patients was started with the help of a local funder, and transport subsidies are now being given to families. The key element of this work has been working with partners in Myanmar and internationally to ensure a strong collaborative effort towards funding and sustainability.

Building Capacity

The twinning partnership has created training opportunities for both doctors and nurses from Yangon. Discussions and mentoring on haematological and solid tumour malignancies have begun regularly by Dr Robert Carr (Guy's Hospital, UK) and Dr Carlos Rodriguez-Galindo (formerly at the Dana Farber/Children's Hospital Boston; now at St Jude Research Hospital is in Memphis USA). This has helped the local team to identify potential specialist doctors and access overseas training to build on their professional development. The nursing team in Boston, led by Lisa Morrissey, has run specialist training workshops in Yangon as well as regular online discussions with the local nurses. The training has been developed following a baseline assessment in 2014 of the needs and priorities for local development. A range of very keen nurses from Boston have become involved and will aim to increase the nursing capacity in the unit. There has also been a focus on developing capacity and expertise in pathology; members of the team have received focused training, which will continue with twinning support from the international partners. Psychology and education staff from the Evelina Children's Hospital (London) have been advising on the need for psycho-social support for patients, families and staff. They have supported the work of play leaders at Yangon Children's Hospital, and World Child Cancer supported in 2016 the opening of a new hospital school, the employment of teachers, and provision of classroom and bedside teaching.

Key Roles

World Child Cancer funds a database manager and Yangon Children's Hospital has initiated a formal patient database

for the unit. This helps with analysis of outcomes, patient demography, workload burden and provision of critical data for healthcare planners. The charity is also supporting a social worker role to assist families with transport arrangements, follow-up visits, and sending reminders for clinic attendance. A new programme manager employed by World Child Cancer is responsible for developing programme plans, overseeing budgets, completing donor reports and managing the non-medical aspects of the programme.

Awareness and Advocacy

Awareness efforts have been scaled-up to reach remote regions and focus on GPs in the country, who need to be informed of the early warning signs of childhood cancer and reduce any delay in diagnosis. Advocacy with policy makers and hospital administration includes a focus on the need for a nurse educator role on the ward. A high-level workshop was recently held in Myanmar, jointly organised by the World Health Organisation, International Society for

Paediatric Oncology (SIOP), Childhood Cancer International (CCI), World Child Cancer and St Jude Children's Research Hospital. The meeting focused on the development of a national cancer strategy, the next stage being to develop an implementation plan for the agreed priority areas.

Conclusion

The programme designed to strengthen childhood cancer services in Myanmar as a collaborative effort has become a multi-dimensional complex strategy, with the aim of improving services in the long-term. Ensuring sustainability relies on the strength of the partnerships, communication between stakeholders and continuing funding for this work, with the realisation that the changes within this challenging environment will take many years. World Child Cancer is committed to supporting Yangon Children's Hospital, and hopefully extending this support to other centres in the country to ensure that every child with cancer can access the care they need.

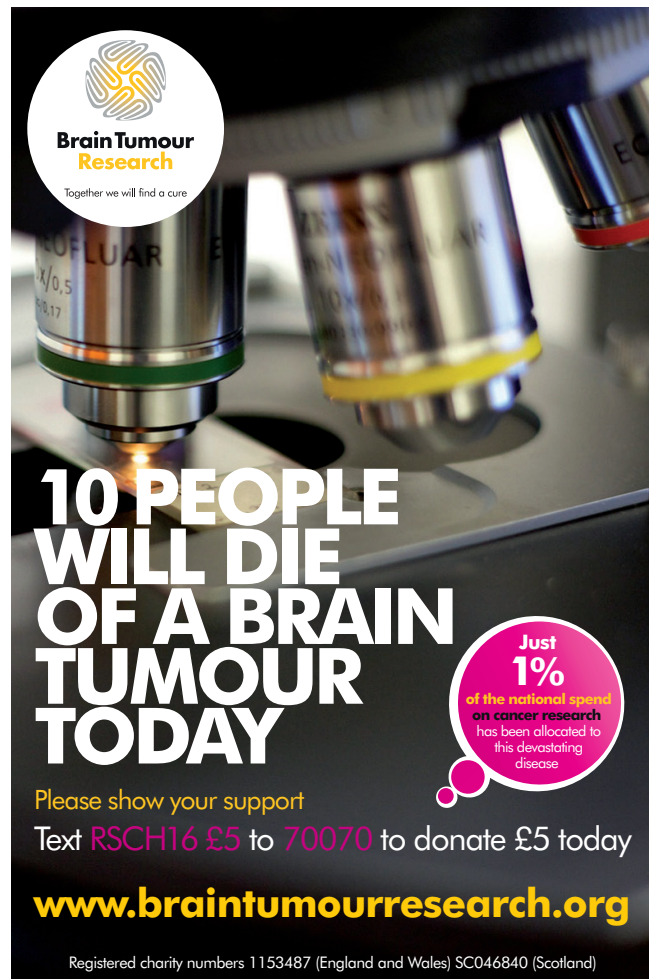
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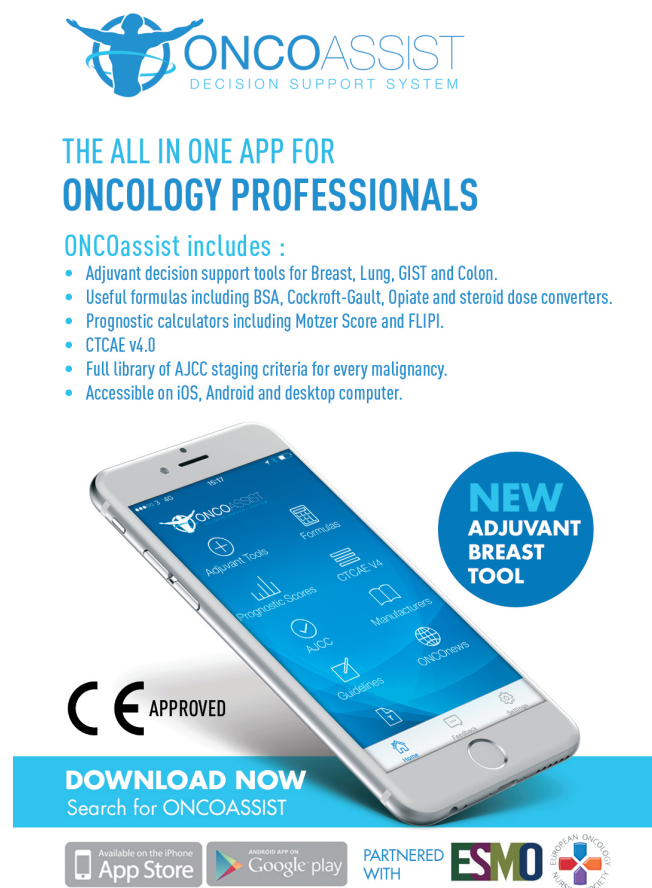
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