

## **14<sup>th</sup> Asia Pacific Hospice Palliative Care Conference Report for APHN Rosalie Shaw Travel Scholarship**

- by Look Mei Ling

### Day 1

The 14<sup>th</sup> Asia Pacific Hospice Palliative Care Conference kicked off for the first time as an online conference, on 13<sup>th</sup> November 2021 morning, broadcasting from Japan, the land of the rising sun. The day started with the opening ceremony by Dr Yasuo Shima and Associate Professor Ghauri Aggarwal, welcoming the participants, followed by a recorded message from WHO on universal health coverage.

For the first plenary, Dr Frank Brennan from Sydney, Australia brought the participants through an insightful journey starting right from the beginning with the need for end-of-life care, and evolving through the recognition and development of palliative care, embracing the conference theme and title of his plenary, "Building Bridges: Hospice Palliative Care Beyond Borders". He touched on the needs, history and development over time with mention of landmark publications like The Lancet Commission Report on access to palliative care and the WHPCA Global Atlas of palliative care, recognizing global inequalities in access to care. He also highlighted the core principles, as well as the limitations of taking only one universal approach to such a diverse population and needs. This was followed by a walk through the inclusion of non-cancer palliative care, in particular renal supportive care and palliative care in neurology, as well as in the setting of HIV, heart and lung disease. At its peak, inclusion of palliative care as a component of comprehensive care and human rights, including as a standard in the event of humanitarian emergencies and health crisis, marks the increasing recognition of the importance of palliative care.

Dr Ryuichi Sekine and Dr Rumalie Corvera chaired the first concurrent session on "Palliative Care in the COVID-19 era", where Dr Shinichiro Morioka gave an account of the challenges and necessary palliative care approach in COVID-19. He shared an interesting case presentation which highlighted some important clinical points in COVID-19 infection, such as the course of disease and symptoms like "silent hypoxia". Challenges included the need for remote communication with family due to restrictions to contain infections. Advance care planning (ACP) became even more important in this setting, before patients deteriorate. Another challenge in such a pandemic is the need to allocate scarce resources and this involves ethical decision making, in addition to good communication. The 3 subsequent speakers, Dr Brian Le from Melbourne, Australia, Dr Rumalie Corvera, the session co-chair who is from Philippines and Dr Naveen Salins from India then gave the participants an overview of the situation in their own country; Australia, Philippines and India respectively. The challenges were very similar to those in Japan, highlighted earlier by Dr Morioka. In addition, admission and visitation by families to palliative care units were difficult with patients presenting with symptoms that may mimic COVID-19, requiring isolation, while policies restrict visitors including the need for quarantine for families travelling in from other states or countries. It became difficult for the team to support each other due to the need for social distancing. In the Philippines, the high numbers of healthcare providers getting infected with COVID-19 and succumbing to it add to the difficulties in providing care, with fear, low morale and social stigmatisation running high. This has led to the team there coming out stronger, with stronger team support and development of numerous guidelines and algorithms for palliative care management of COVID-19 patients and their families. For India, the major challenge was triaging the huge number of COVID-19 patients in a very limited resource setting and this led to their development of COPE-CP, an

algorithm and checklist to facilitate triaging of patients, which also included a communication guide for discussing the triaging outcome with patients and their family and also a criteria checklist for palliative care referral.

The next concurrent session on “Breathlessness and its impact on quality of life” started on time, chaired by Dr Takashi Yamaguchi and Dr Frank Brennan. It started with an overview of chronic breathlessness, including its definition and principles of management to address the underlying cause, instituting non-pharmacological measures and finally focusing on the use of opioid in alleviating the symptom. The speaker, Dr Diana Ferreira from Australia gave a comprehensive run through of studies and evidences supporting the efficacy and safety of Morphine in chronic breathlessness, in particular for the once daily sustain released formulation. It was highlighted that the strongest evidence of benefit is in the chronic obstructive pulmonary disease subset, with recommendation to titrate to effect on a weekly basis to ensure achieving maximum effect but keeping in mind that efficacy becomes limited above a dose of 30mg per day. Dr Shogo Oishi, from Japan, then talked about the management of dyspnoea in heart failure, including the model of care where curative anti-failure treatment is continued together with palliative symptom management up to the end of life. He presented data of parenteral morphine use in his institution where they found statistically significant improvement in terms of breathlessness, with good safety profile. This was given alongside heart failure treatment like diuretics and inotropes, as well as the addition of sedatives to further improve the control of breathlessness. The final speaker, Dr Jun Kako, also from Japan, touched on non-pharmacological treatment of dyspnoea in cancer patients. He provided evidence-based approach that included increasing airflow to the face using a fan and breathing techniques that are recommended in current major oncological guidelines. There was sufficient time at the end of this session for an interesting discussion on the limitations and lack of good quality evidence base in management of chronic breathlessness, highlighting the urgency for future research addressing this deficiency.

The third concurrent session of the day was on “Holistic care for patients and families in end-of-life” and this was chaired by Ms Yukie Kurihara and Professor Amy Chow. For this session, a diverse range of speakers from different countries touched on specific palliative care issues in their respective countries. Dr Carl Becker gave an account of the development of end of life decision-making and ACP in Japan, including the effect of culture and difficulties in implementing advanced care planning from different perspectives. Dr Thomas LeBlanc from United States then touched on the challenges and opportunities to provide palliative care in Haematology units in the United States, where he finds that starting with symptom management and gaining trust is the way to go before moving forward to more holistic palliative care provision. Dr Sang-Yeon Suh then took the participants through the interesting series of events leading to decisions on life-sustaining treatment and ACP implementation in Korea. This was followed by elaboration on the laws promoting palliative care in Taiwan by Dr Ping-Jen Chen, including on the positive impact of the Hospice Palliative Care Act and the specifics of Patient Autonomy Act. It was concluded that holistic care is influenced by many factors like culture, disease state and social context, and hence need to be highly individualised.

Developing evidence for clinical palliative care was the topic of the fourth concurrent session, chaired by Dr Yusuke Takagi with Dr Shao-Yi Cheng. Dr Masanori Mori from Japan talked about the East-Asian collaborative studies in palliative care (EASSED study), a multicentred cohort study being finalised

for publication. He highlighted on the challenges and key factors to successful collaboration like good teamwork, scientific rigidity, administrative support and capacity building for growth. Dr Chetna Malhotra from Singapore went through the learnings from the multi-country APPROACH study which looked at suffering, satisfaction level, decision making and mental health issues among palliative care patients. Professor Jane Phillips then gave the Australian perspective on improving palliative care through global collaboration for research, pointing out the benefits, highlighting some examples of international research collaboration including their strengths and weaknesses, and also the need for commitment from team members. Final speaker Professor Chia-Chin Lin from Taiwan focused on evidence-based end-of-life care in long-term care facilities and mentioned about using the RE-AIM framework for implementation studies.

The next concurrent session moved on to touch on “Consensus in quality palliative care”. This was chaired by Dr Hideyuki Kashiwagi and Mr Fan Kwan. Dr Barbara Daveson from Australia introduced the essential ingredients and key considerations regarding Australia’s Palliative Care Outcomes Collaboration (PCOC), which is widely implemented in Australia, as well as adapted for use and benchmarking in some other countries. Professor Ying Wei Wang then talked about the Taiwan experience in adopting, training and implementing PCOC in Taiwan. The final speaker of the session, Dr Mitsunori Miyashita gave details on the development of a pilot patient-reported outcomes measures collection system by hospital-based palliative care team.

After 5 concurrent sessions, it was time for the second plenary of the day, which was on national evaluation of the quality of palliative care and this was chaired by Dr Mitsunori Miyashita and Dr Jho Hyun Jung. Here, speakers from United Kingdom, India and Australia presented on their country data and perspective. Dr Fliss Murtagh from United Kingdom highlighted the importance of deciding appropriate outcome measures including phases of illness, functional outcome measures, Integrated Palliative Care Outcome Scale (IPOS) and Edmonton Symptom Assessment Scale (ESAS), where individual level outcome measures can improve patient care and demonstrate the impact of palliative care. Dr Tushti Bhardwaj elaborated on the tedious but rewarding process of translating IPOS to Hindi and subsequently adapting and using it in India. Dr Barbara Daveson’s second session of the day gave further details of the development, funding, routine practice and quality improvement, training of facilitators, as well as evaluation of PCOC implementation in Australia, which has been noted to contribute to statistically and clinically significant outcomes.

The long day concluded with the sixth concurrent session on complementary, alternative, and integrative medicine in palliative care and a final plenary on early palliative care. The concurrent session was chaired by Dr Kozue Suzuki with Dr Mandy Paris-Pipper. Dr Chung-Hua Hsu talked about traditional Chinese medicine in palliative care in Taiwan, Dr Raghavendra Rao Mohan touched on AYUSH in palliative care in India, Dr Erika Nakanishi went through the indigenous faiths and medicine in Japan and finally Dr Tess Huia Moeke-Maxwell focused on indigenous holistic Māori palliative care approach in New Zealand. The final plenary saw Dr Thomas LeBlanc from the United States speaking for the second time, on “Integrated Palliative Care in Oncology: where do we go from here” and this was chaired by Dr Yu Uneno with Dr Ramaswamy Akhileswaran.

## Day 2

The second day saw a new line up of interesting plenaries and concurrent sessions. The first plenary of the day covered the topic of Advanced Care Planning (ACP) with updates from the United States, Hong Kong and Singapore. This was chaired by Dr Megumi Kishino and Dr Raymond Ng Han Lip. Dr Raymond was also one of the three speakers for the session, where he gave an update on the ACP development in Singapore, touching on their Living Matters program including their effort in training, promoting and evaluation of their ACP implementation. He also went through some available evidences looking at ACP use and goals of care discussion in promoting better patient outcome. Also in this session, Dr Rachelle Bernacki and Ms Helen Chan elaborated on the Serious Illness Care Program in the United States and in Hong Kong respectively. The differences between ACP discussion and goals of care discussion were highlighted. Outcomes of studies evaluating their implementation was also discussed.

The concurrent session that follows continued addressing the big topic of ACP, this time focusing on the real-world experience with global perspectives from United States, Taiwan, Japan and Thailand. Dr Jun Hamano and Dr Rachelle Bernacki chaired this session. Dr Rachelle Bernacki also gave her second talk for the day about the training of clinicians to conduct the serious illness conversations she introduced earlier. This involved a training guide that has 10 steps that take into account the 4 adult learning methods involving emotional engagement, cognitive learning, skills training and modelling. Then, Dr Cheng-Pei Lin gave an overview of the ACP program in Taiwan, going through the development, cultural adaptation and implementation of it. He highlighted the need to involve families in discussion and being aware of social norms in the Asian context. For Japan, Dr Jun Miyashita talked about the timing of ACP discussion in the local context in relation to Japanese culture and custom. He looked at the healthcare providers' versus the patients' perspectives of ACP, where discrepancies need to be addressed to promote optimal timing of ACP discussions. And finally, participants were brought through the process of nationwide implementation of ACP in Thailand under their National Health Commission by Dr Srivieng Pairojkul. In Thailand, palliative care programs are promoted via the Palliative Care Policy and ACP is one of their major key performance indicators (KPI) of health services. The recurring theme of the Asian cultural emphasis on families' role in decision making and care dependence, in addition to the taboo surrounding talking about death, came up multiple times, in contrast to the western culture of self-reliance, autonomy and openness to end of life discussions.

The next session was the HINOHARA memorial lecture, in honour of Dr Shigeaki Hinohara who was instrumental in the initial events leading to the establishment of the Asia Pacific Hospice Palliative Care Network (APHN). Chaired by Dr Akitoshi Hayashi and Associate Professor Cynthia Goh from Singapore, Dr Tatsuya Morita gave an account of his life story from his unique childhood of being different, highlighting the people who touched and influenced his life, to the development of research work that he is passionate about, where his studies were mostly a result of the questions that came up from his daily work of providing palliative care. He reflected that as a clinician, everyday created real questions from real experiences where research is the way to find a solution through the voices of his patients and their family. Dr Rosalie Shaw, with her own background of inspirational personal stories and work in developing palliative care from scratch, then narrated about Dr Hinohara's early life, through to his work and finally his valuable contribution in establishing APHN. He was actively involved in teaching others and publishing books up to the end. His passion for helping people remain inspirational to all.

The next concurrent session was on capacity building in palliative care chaired by Dr Michio Ono and Dr Shirlynn Ho. Here, participants get to hear about the launching of Hospice Palliative Care in Kenya by Ms Juli McGowan Boit. The bulk of work here are related to HIV and AIDS as this is the main burden of morbidity in the region, focusing on access to care and medication, education and training, as well as financial sustainability. This was followed by Dr Shahinur Kabir account of the tele-hospice service established in Bangladesh, with the available evidence base backing its development, looking at the effectiveness and also cost-effectiveness of it. Dr Suresh Kumar gave an update of the palliative care activities in Kerala, India, where a big portion of India palliative care delivery occurs in this region due to strong capacity building in the community and support from the local government. This was done through training programs targeted at the community, enabling a large part of palliative care provision being possible by volunteers in the community. This is then supported by the next level of palliative care through community nurses, non-governmental organisations, and primary health clinics. Finally, we had a run through of the education and training of Hospice Palliative Care Workers in Japan by Dr Yoshihisa Hirakawa. It was noted that hands on educational workshops and support through social media applications were useful for these care workers, as well as use of conversation guides to empower them for difficult conversations.

The topic of developing palliative care services through training, education and advocacy continues in the next plenary. Dr Yoshiyuki Kizawa and Associate Professor Ghauri Aggarwal co-chaired this session. Dr Emmanuel Luyirika from Uganda gave some insight on the palliative care development and delivery in the context of the COVID-19 pandemic in Africa, talking about the initial disruption of services and funds in the already resource poor setting. Subsequent innovative steps taken allowed for reassessment of needs, use of technology and re-engagement of donors for funds to enable continuation of care and training in palliative care. Dr Suraj Perera talked about the palliative care development in Sri Lanka under the Lien Collaborative Project, where the project took a few years of discussion, training and capacity building to develop the program to what it is today, including the inclusion of palliative care as part of the Sri Lanka National Health Policy and then the launching of a National Strategic Palliative Care Policy. This was followed by an update on the network of palliative care in Thailand by Dr Srivieng Pairojkul. It was interesting to see the development of their education program from basic palliative care approach for allied health staff, to general palliative care training and fellowship program for specialist palliative care. Lastly, participants get to learn about the Cancer Treatment Centre Program in India by Dr Sushma Bhatnagar. This program aims to ensure provision of palliative care in all cancer centres in India by training and empowering their own staffs in palliative care provision and ensuring medications availability.

The exciting two-day program draws towards a close with a special lecture by the current chair of APHN, Associate Professor Cynthia Goh, reflecting on the APHN development. The lecture touched on the initial informal meetings, progressing to formalised meetings and conferences, all the initial leaders involved in making it happen, the countries involved, education, research, going through the vision, mission and goals, and most importantly, her dreams and aspirations for APHN in the future. This was followed by the closing ceremony, where Dr Masanori Mori and Dr Etsuko Kita extended their appreciation to all who made the conference a success. The best 15 abstracts out of 300 over received this year was also announced. The conference concluded with an introductory video to the next Asia Pacific Hospice Palliative Care Conference 2023 what will be held in Korea. With a heavy heart, the

conference ended with closing remarks from Dr Ednin Hamzah from Malaysia, Dr Tetsuo Kashiwagi and Dr Yasuo Shima from Japan, as well as Associate Professor Ghauri Aggarwal from Australia.