Paediatric Palliative Nursing in Hong Kong – Adding Life to Days

Connie Tse, Editorial Committee, HKPNA

The Children's Palliative Care Week organised by the Paediatric Department, UCH was held in June 2017. Paediatric Palliative Care (PPC) is a holistic approach aiming at the alleviation of children's pain and symptoms, the physical and emotional distress of child and family. It is not talking about the care in the last six months of life, but with the goal of improving the quality of life while still seeking curative treatment along the full continuum of the life course.

Nowadays, with the advances in medical technologies, children with complex medical conditions or congenital anomalies can live longer life. Therefore, PPC should be started early once the diagnosis is made.

Paediatric patients have a very diverse disease trajectories and the outcome of each child is hard to foretell. The disease pattern evolves along the child’s growth and development is unpredictable. In addition, besides medical care, the needs of care providing to children extend to include education, schooling, play, psychological and physical development.

On 15 June 2017, a special day seminar of Paediatric Palliative Nursing was held at Caritas Medical Centre. Nursing representatives from Caritas Medical Centre, United Christian Hospital, Queen Elizabeth Hospital, Prince of Wales Hospital and Queen Mary Hospital as well as the overseas speakers from Florida, the USA presented their latest works and service development in PPC. Strategies on how to overcome the hurdles of providing quality PPC were shared. Then a visit to Polytechnic University to meet up with Professor Frances Wong, the President of the HK Academy of Nursing was followed.

It has been an excellent opportunity for paediatric nurses to ignite the inspirations, to catch up with the concepts of PPC development, re-engineer the paediatric service system to provide holistic family-centered care for children with complex needs by adding life to their days.
Adding Life to Days – Implementation of Advance Care Planning in Hospital

NG Wa Yung APN, LEUNG Mei Mui NO, MA Po King DOM & YOUNG Mei Wan WM, UCH (Paed & Adol Med)

The life expectancy of children with life-limiting conditions may last for years or decades. The Advance Care Planning (ACP) would help to support and enhance both the quality of life (QOL) and quality end-of-life care. ACP for children integrates the principles of palliative care in a holistic family-centered approach.

A 12-year-old boy called Wally who was born in UCH, is suffered from Centronuclear Myopathy and remains bed bound. He cannot speak but produces incomprehensible sounds when happy. He is mechanically ventilatory supported via tracheostomy with artificial gastrostomy feeding. Parents were not HK citizens but residents in Mainland China. Communications between the healthcare team and the family has been very limited. Wally has been staying in the general paediatric ward since 2010.

In 2015, Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR) order was reviewed between Wally’s mother and the primary doctor (PD) when sudden deteriorations occurred repeatedly. Later, mother put a red packet as blessing under Wally’s pillow, weeping helplessly. She presented her anticipatory-grief by telling the primary nurse that a fortune-teller said, “Wally could not live past the age of 12-year-old”.

Wally’s family eventually granted one-way permit to reside in HK in early 2017. More frequent visits enhanced the rapport building. As Wally had seizures since last year with increasing frequency and duration recently, parents were invited to join the ACP conference on May 5 with multi-disciplines. PD shared information on course of Wally’s disease and prognosis. The conversation was framed on optimizing his QOL. According to Department/Hospital Policy Guidance, all possible emergent situations that the child may encounter were indicated. Detailed treatment options with pictures illustration were shown to parents. Written consensus document was kept inside the medical records for colleagues’ reference and access to ensure parents’ choices are respected. Another important discussion is parent’s wishes. Mother expressed that she was well prepared should Wally’s condition deteriorate but worried about the father and his elder sister’s reactions. In collaboration with MSW and chaplain, grief support would be offered to them. Since mother wishes to bring Wally outside hospital to the seaside or park, which seems impossible with his status, therefore, we arranged a celebration party for Wally’s family on Mother’s Day in our day center.

We provided a sea view backdrop decoration for family’s photo taking. Wally produced incomprehensible sounds to show his happiness all day. His mother kept smiling in the party. She expressed that she had been at ease from mental burden after the ACP discussion, which we found impressive and meaningful to us.

ACP is more than DNACPR and does not mean giving up the child. Wally and his mother’s cheerful expressions told us the fact of implementing the holistic ACP. It helps to reduce unnecessary sufferings, promote QOL, support the anticipatory grief, and enrich parents’ sense of control. Let’s strive to add days to life by establishing and implementing the PPC standards in the patients under our care.

Adding Life to Days – Integrated Care and Support in the Community

Yam Wai Lin, APN, UCH (Paed & Adol Med)

Nowadays, the advancement in medical technology enables children with life-limiting diseases or medical complexities to spend lesser days in the hospital, and more days at home and in school. However, caring for these children in the community requires a lot of professional support to the parents and the school.

Integrated Care and Community Support for Children with Special Health Care Needs (ICCS) Program began in 2014 in Kowloon East Cluster. As the paediatric nurse who runs this program, I work in close liaison with all care partners to enhance the communication of the needs and support services among the hospital team, the school and the parents. I visit the schools regularly. I talk with the children, the teachers, the house parents, the therapists and the social worker. The difficulties and problems related to the student’s care in the school would be addressed and solved. These result in fewer admissions, shorter hospital stays and increased confidence of carers. Furthermore, not only do both parents’ and the students’ level of anxieties reduce, but also they could resume their normal social lives earlier for better outcomes. Additionally, parents and the school carers could have better understanding of the disease of the child through the case meetings. They are also better prepared to face the ‘what if’ situation in case the child’s condition deteriorates.

With the interdisciplinary care team approach, support will be provided to the family along the way. Therefore, my role as a paediatric nurse goes beyond the walls of the hospital and extends to the community, to the home and into the special schools, contributing by adding life to their days through the ICCS.
Strategies to Increase Protective Factors Among Children and Adolescents in the School Communities: Impact of the School Nurse Role

Regina Lee RN, PhD, President, Hong Kong School Nurses Association

Introduction

Ongoing changes in health care continue to impact the way care is delivered. Demonstrating the impact of the advanced practice nurses (APN) role is an essential component of professional practice. The Institute of Medicine (IOM) report on the future of nursing role highlighted the importance of promoting the ability of APN to practice to the full extent of their education and training and to identify nurses’ contributions to delivering high-quality care (IOM, 2010).

In the school communities, nurses have long known that health education and health promotion activities can contribute to students’ academic success and emotional well-being. Students are more likely to engage in healthy behaviors and succeed academically when they feel connected to school. Demonstrating APN impact requires an assessment of the structures, processes, and outcomes associated with advanced nursing practice has resulted from the growing emphasis on outcomes that have become a recognized component of the majority of health care initiatives.

Impact of the school nurse role in promoting child health via implementing a Health Ambassador Scheme

In the past decade, Hong Kong School Nurses Association has been collaborating with School of Nursing, The Hong Kong Polytechnic University, World Health Organization for Community Health Services to implement the Health Ambassador Scheme (HAS) with the aim that university nursing students (mentors) train primary school students (mentees) becoming health ambassadors so that they can promote healthy lifestyle behaviors and psychosocial well-being while enhancing students’ learning in the school communities.

The goal of the HAS is to cultivate social responsibility to our future nursing leaders through mentorship, career exposure and leadership development. It is an 8-month mentoring program whereby primary school students are educated on a variety of health topics including nutrition, cardiopulmonary resuscitation (CPR) and health assessment skills. The aim of the HAS is to promote leadership development and tiered mentorship through raising awareness about health inequalities that disproportionately affect minority group in the school communities.
It is expected that disseminating important health messages based on APN role in school health to raise the awareness of healthy lifestyles should start earlier in younger age — Develop innovative health promotion materials to enhance healthy lifestyle for advocacy of school health activities through delivery of health knowledge and nutritional education to promote the healthy snacks and regular exercise. Identifying health risk behaviors and factors are essential among the primary school students so that early intervention can be planned appropriately via HAS activities to:

1) Create a supportive environment for health and well-being;
2) Establish networks among the primary schools to promote healthy development of school aged children.

The mentees (primary school students) and service recipients (school principals and teachers) were surveyed using pre-and post-tests and interviewed in focus groups on the impact of HAS on the students’ and their peers' lifestyle behaviors and psychosocial well-beings. The findings were very positive and encouraging. Both nursing students and primary school students developed a sense of ownership of the planned health education and promotion activates of the HAS and a commitment to its success. As the HAS project supervisor and leader of this innovative project, it was an absolute honor to demonstrate the expanded role of an advanced practice nurse via the implementation of the HAS in the school communities in Hong Kong.

I would like to end this story by sharing Conrad and Hedin’s quote: "Reflection ...can allow program experiences to live on in the students' lives in new experiences and new learning." To say that experience is a good teacher, however, does not imply that it is easy, as "Experience is not what happens to a man, it is what a man does with what happened to him".

References


The Joint Annual Research & Scientific Meeting 2017

Lee Wan Ming, Editorial Committee, HKPNA

For the first time, four paediatric medical and nursing professional bodies, namely, the Hong Kong Paediatric Society (HKPS), Hong Kong College of Paediatricians (HKCP), Hong Kong Paediatric Nurses Association (HKPNA) and Hong Kong College of Paediatric Nursing (HKCPN) jointly organized the Joint Annual Research & Scientific Meeting on 19 August 2017 (Saturday) at the Postgraduate Education Centre, Prince of Wales Hospital. The chairman of the organizing committee Prof. Godfrey Chan described, this signifies that all the professionals are working towards the common goal in improving the holistic care of paediatric population.

The meeting ran smoothly and successfully brought to the close. More than 40 abstracts were submitted in the oral or poster presentation on different academic institutions and public hospitals. Total 18 authors gave oral presentations on their good works. The contents covered a wide range of topics from scientific researches to clinical studies. Dr. Choi Yuen Wan, Philemon M.D., J.P., the Founder of Breakthrough Ltd, and the President of Youth Global Network Ltd., was invited to give the keynote lecture “Youth Development in Hong Kong - the way ahead”. In his speech, he pointed out that young people of HK will face tremendous challenges as approaching the new phase in the 21st Century. Focusing in the 4 realms of youth development -“educational, health, economic and political” , Dr Choi has quoted a few distinguished views from international renowned writers and seven case studies to illustrate the gaps and direction in how to enhance the development of the new generations in HK. He has given insights into the strategic roles that our paediatric health professionals could play, in particular, submission of proposal and conduction of “Policy Action Research”, systematic development of “Community Paediatrics”, professional training related to Youth Development and partnership advocacy for the youth and children.
Ms Luk reflected as follows:

- Honestly, I am just one of the dedicated nursing team members. Effective and quality nursing services cannot be sustainable with one person’s effort. The award should be shared amongst all the nurses with team spirit in one accord, recognizing our dedication to the clients, patients and their relatives.

- Participation in community work has enabled me to work closely with other disciplines for anticipatory problem solving skills. So, there are always wonderful returns in personal growth when we have participated wholeheartedly.

- I take this opportunity to extend my hearty gratitude to my teachers, supervisors and colleagues who led my way from a post-secondary school graduate to a professional nurse. Their coaching through theoretical teaching coupled with life examples had guided me to walk steadily.

- I thank my patients as well. Their appreciation and smiles encourage me to keep my high spirit. Their criticism adds fuel to let me know more about myself and where to improve.

- Let us work hand in hand for the advancement of nursing, as the development of advanced nursing practice enables us to enhance our knowledge and skills in specialized areas with more autonomy and responsibilities, making a difference to each patient encounter.

Joint Annual General Meeting (AGM) and Annual Dinner of HKPNA & HKCPN 2017

Cheng Sau Wai, Editorial Committee, HKPNA

In celebration of the 17th Anniversary, Hong Kong Paediatric Nurses Association (HKPNA) and the 5th Anniversary, Hong Kong College of Paediatric Nursing (HKCPN), a joint AGM and annual dinner was held on 29th July 2017 at the Royal Plaza Hotel. Over 110 guests and members attended the event.

The guest of Honor Prof. Sophia Chan, JP (Secretary for Food and Health Bureau of the Hong Kong Special Administrative Region Government) delivered an opening speech. She praised the concerted effort and support of HKPNA and HKCPN to strive for the professional growth of Hong Kong paediatric nursing over this last decade and a half.

The two presidents Ms. Iris Yeung and Ms. Susanna Lee expressed their sincere gratitude to all the guests joining this special joint annual dinner. They expressed the deep appreciation to all honorary advisors for their inspirational guidance and unfailing support. An extension of big thanks was made to all board members, committee members and hospital coordinators for their committed works and valuable opinions.

The dinner was enriched with a slide show of the HKPNA & HKCPN and the marvelous Indian dance performance by Ms. Pearl Sze, a member from PYNEH. People were amazed at the hidden talent as a dancer in Ms Sze. The lovely moment was filled with warm chatting, catching up with old friends and photo shootings.
**Professional Development Activities**

- **Professional CME Meetings on Child Health 2017** co-organized with HK Paediatric Foundation, was held on 9/5, 6/6, 4/7, 1/8 & 5/9/2017 at various venues, attendance 18, 17, 20, 18 & 23 respectively.
- **Update Series on Child Health 2017** co-organized with HK Paediatric Society and HK College of Paediatricians, was held on 29/4, 20/5, 24/6, 22/7, 26/8 & 16/9 at Jordan Valley St. Joseph’s Catholic Primary School, attendance 271, 282, 300, 277, 341, 290.
- **Short Course on Paediatric Endocrine: Lecture 3 - Nursing Management for Paediatric Patient with DM and Common Endocrine Problems** was held on 19/5/2017 in QEH, attendance 39.
- **Practical Paediatric Cardiology Course 2017** co-organized with HK Society of Paediatric Cardiology, was held on 27/5/2017, at Hyatt Regency at K11 Tsim Sha Tusi, attendance 74.
- **Joint Annual Research and Scientific Meeting** co-organized with HK College of Paediatric Nursing, HK Paediatric Society and HK College of Paediatricians, was held on 19/8/2017 in PWH, attendance 37.

**Orthcoming Events**

- **Professional CME Meeting on Child Health 2017- Update on the Diagnosis and Management of Squint in Children** co-organized with HK Paediatric Foundation will be held on 10/10/2017 at Chairman’s Suite and Executive Room, 38th Floor, World Trade Centre Club, Causeway Bay, Hong Kong.
- **Hong Kong Society for Adolescent Health 12th Annual General Meeting cum Seminar** co-organized with HK Society for Adolescent Health will be held on 14/10/2017 at Hall, 8/F, Block G PMH.
- **Hong Kong Dermatology Symposium 2017** organized by HK Dermatology Foundation, Department of Microbiology CUHK, Department of Paed & Adol Med UCH as well as HK Paediatric and Adolescent Dermatology Society will be held on 21-22/10/2017 at Postgraduate Education Centre, PWH.
- **9th Cross-Straits Paediatric Respiriology Congress cum 20th HKSPRA Annual Scientific Meeting**, organized by HK Society of Paediatric Respiriology and Allergy, will be held on 21 – 22 October 2017 in the Cordis Hong Kong.
- **3rd Asia Pacific Pediatric Nursing Conference 2017** will be held on 20-21/11/2017 in Bangkok. Please visit www.appnc2017.com for details.

**Renewal & Application of Membership**

Registered and Enrolled nurses who have experience in paediatric care are welcome as members. Any nursing undergraduate and pupil nurse, of the universities and nursing schools, who has interest in paediatric nursing are also welcome.

Please complete the **Membership Application/Renewal Form** and return it to Ms Caroline Lee, Hon. Dep. Secretary, 5404, QEH together with a cheque made payable to “Hong Kong Paediatric Nurses Association Ltd”. Application forms can be obtained from HKPNA Hospital Coordinators or downloaded from web site [http://www.hkpna.com.hk](http://www.hkpna.com.hk). Kindly fill in your email address when returning the completed form, so that we can keep you informed of the activity / course information updates.

Life Members are also welcome to update any personal particulars annually and furnish your email address using the same form.