

LCQ11: Paediatric palliative care

Following is a question by the Hon Martin Liao and a written reply by the Secretary for Food and Health, Professor Sophia Chan, in the Legislative Council today (June 23):

Question:

According to the definition of the World Health Organisation, palliative care aims to provide assessment and treatment services to patients with life-threatening and life-limiting conditions to prevent and relieve suffering of patients, thereby improving the quality of life for them and their family members. Some patient groups have pointed out that paediatric palliative care services are currently provided by the paediatric departments in various public hospitals instead of allied health teams, which is not conducive to the enhancement of service quality and the accumulation and passing on of the relevant experience by healthcare personnel. In this connection, will the Government inform this Council:

(1) whether it knows the number of children with life-threatening and life-limiting conditions who received palliative care at public hospitals in each of the past five years, with a breakdown by the type of diseases they suffered from (e.g. cancers, neurological disorders and respiratory diseases) and by the type of services provided to them;

(2) as the Hospital Authority (HA) indicated in 2018 that the Hong Kong Children's Hospital, upon commissioning, would set up a centrally coordinated paediatric palliative care team comprising multidisciplinary professionals responsible for coordinating territory-wide paediatric palliative care services, whether it knows the progress of the relevant work, and if the HA has formulated key performance indicators for the work of the team; if the HA has, of the details; if not, the reasons for that;

(3) in respect of the training on paediatric palliative care services provided by the HA to healthcare personnel, whether it knows if the HA (i) reviewed the effectiveness of such training and (ii) enriched the training contents, in the past two years, with a view to enhancing service quality; if the HA did, of the details; if not, the reasons for that; and

(4) whether it has considered strengthening, at the community level through District Health Centres and primary care providers, the support provided to children who are receiving palliative care; if so, of the details; if not, the reasons for that?

Reply:

President,

My reply to the various parts of the question raised by Hon Martin Liao

is as follows:

(1) As the Hospital Authority (HA) generally looks after children suffering from life-limiting illnesses through the respective paediatric sub-specialty teams, and delivers various levels of palliative care through multi-disciplinary service teams according to needs of patients, the HA's medical system does not have a specific diagnosis code for children with life-limiting conditions receiving paediatric palliative care in public hospitals. The HA hence does not maintain figures in this regard.

(2) The HA has established a dedicated multi-disciplinary paediatric palliative care team in the Hong Kong Children's Hospital (HKCH) to provide more comprehensive, timely and well-coordinated service to children with life-limiting and life-threatening conditions and their families. The team has been operating since March 2019, with members including paediatricians, nurses and medical social workers. The team also provides service in collaboration with allied health professionals (including occupational therapists, physiotherapists, clinical psychologists and dietitians etc.) and members of spiritual care teams of different religions and faith.

Under the current operation, doctors in the clinical team would refer suitable patients to the paediatric palliative care team for follow-up simultaneously. Taking into account the current condition and wishes of the patients and their families, the team would tailor-make a personalised service that provides holistic care to addresses their physical, psychological, social and spiritual needs and improve their quality of life. The scope of services includes advance care planning discussion, co-ordination of complicated care process, symptom relief, emotional support, home visits, telephone hotline, end-of-life care and bereavement counselling etc. The team would also refer patients to suitable non-governmental organisations and liaise with schools to enhance community support.

The paediatric palliative care team is commencing services in phases. At present, it mainly supports families of paediatric patients of haematology and oncology, cardiology, and nephrology at HKCH. Up to now, the team has served more than 140 families, and provided more than 5 300 consultations (including inpatient medical consultations, specialist outpatient clinic attendances and home visits). The team will gradually expand its services as planned. The ultimate goal is to co-ordinate territory-wide paediatric palliative care services in the HA, and align treatment protocols and referral guidelines to ensure service quality and continuity in the paediatric service network.

(3) The paediatric palliative care team of HKCH would provide training to their clinical staff, including case studies, lectures, and clinical applications etc., to enhance their knowledge of palliative care so as to better attend to patients' needs.

All paediatric trainees joining the higher training programme of the Hong Kong College of Paediatricians since July 2020 must complete a training

module on paediatric palliative care before fellowship. In addition, the Hong Kong College of Paediatric Nursing also offers paediatric palliative care courses.

(4) In a bid to shift the emphasis of the present healthcare system and mindset from treatment-oriented to prevention-focused, the Food and Health Bureau is now setting up District Health Centres ("DHCs") in all 18 districts across the territory. Through DHCs, the Government aims to encourage members of the public to be health conscious and take precautionary measures through early identification of health problems with an aim of enhancing their capability in self-management of health and chronic disease. In accordance with the advice from the Steering Committee on Primary Healthcare Development (Steering Committee), resources for DHCs are currently focused towards tackling the most prevalent chronic diseases and health risk factors that consume substantial medical resources.

Meanwhile, DHCs are also positioned as a district hub for connecting various public and private primary healthcare services (including paediatric palliative care and related support services) and non-governmental organisations in the community. Free consultation and counselling services are provided to the public by healthcare professionals in DHCs, such as nurses, social workers, pharmacists, etc. They also strive to connect service providers in the district in a co-ordinated manner and make referral for members of the public in need when necessary.

We will continue to evaluate the effectiveness of DHCs services by evidence-based approach and consider to further expand the provision of other primary healthcare services through DHCs under the guidance of the Steering Committee.