

# PALLIATIVE CARE FOR CHILD WITH CYANOTIC CONGENITAL HEART DISEASE (TRICUSPID ATRESIA AND PULMONARY STENOSIS)

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## Background & Aims:

- Palliative care is needed for many children with serious conditions to address their **physical, spiritual, and psychosocial needs**, it focusses on relieving pain and other symptoms as well as **improving quality of life**
- Palliative care is appropriate for children with a wide variety of serious illnesses: neonatal conditions (e.g. extreme prematurity), congenital anomalies, HIV/AIDS, cancer, and severe neurological conditions.
- The pediatric palliative care program in southeastern Bangladesh, includes pediatric, psychosocial, and a home-based palliative care team, consisting of a nurse and a 24-7 telephone service.

## Case Description:

- A previously healthy 5-year-old girl presented with progressive fatigue over the past 6 months, and now becomes tired with walking.
- No history of fever or TB contact.

## Investigations:

- Cardiac ultrasound images were obtained and reviewed by a cardiologist via telemedicine and tricuspid atresia and pulmonary stenosis (cyanotic congenital heart disease) was diagnosed.

## Management

- Cardiac surgery was not available
- Cardiology recommended propranolol, which was started
- Diuretics and supplemental oxygen are not indicated for this cardiac condition
- Palliative care consultation was obtained through telemedicine

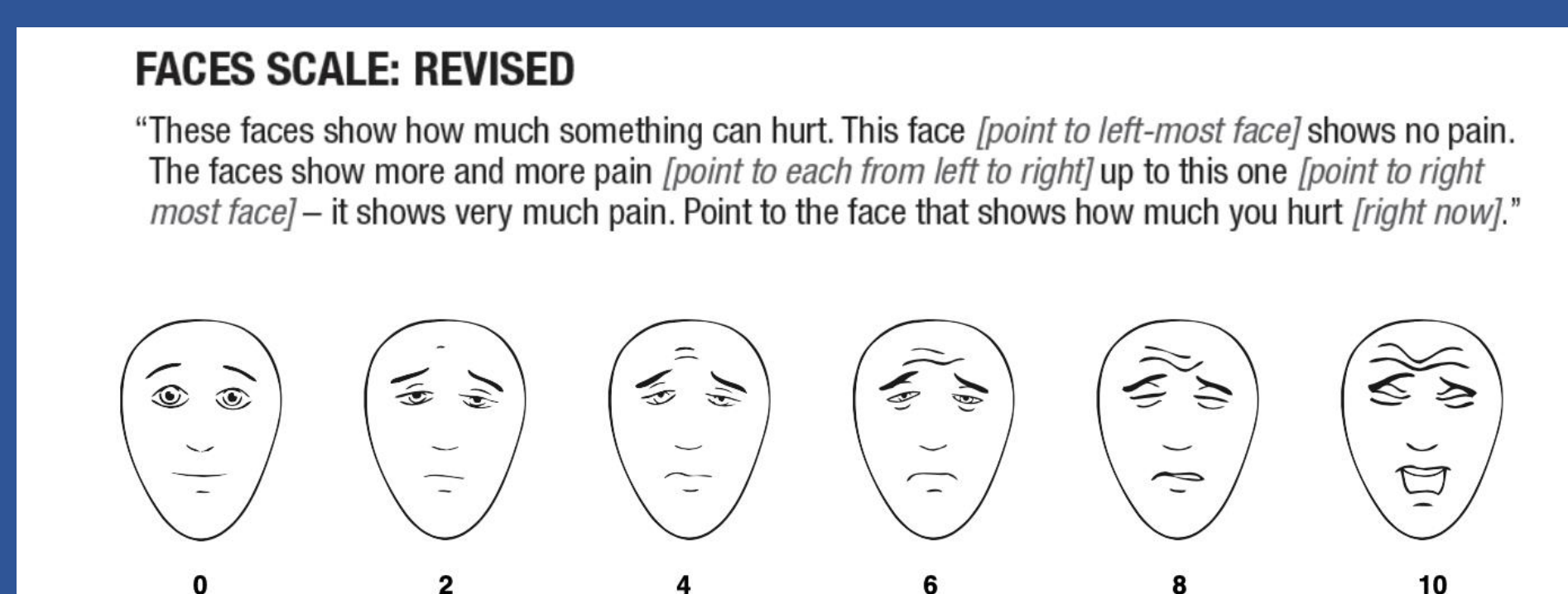
## Palliative Care Supports:

### Communication

- Her parents were counselled about her condition and prognosis and understood her condition was not curable
- They preferred to spend time together as a family at home, so that the child could spend time with her 2-year-old sister and grandparents
- After diagnosis she was discharged home and followed up by the palliative home care team

### Physical Symptoms

- Dyspnea:** she developed dyspnea 1 month after diagnosis which was managed with oral morphine (0.1mg/kg/dose) every 6 hrs
- Pain/Irritability:** was assessed with the faces pain scale-revised managed with oral paracetamol (10mg/kg/dose) every 6 hrs



### Emotional, Social Concerns

- Both parents were affectionate with their daughter and enjoyed playing with her
- Parents were anxious as she was losing weight and looked thin, the homecare team provided additional foods that the child enjoyed (eggs) and encouraged the parents to offer smaller more frequent meals
- Family had lack of familiarity with medical treatment, limited education and no previous exposure to health care system

## Pediatric Palliative Care



*Palliative care is more than just End of Life Care*

*Palliative care should begin at the time of diagnosis and can continue alongside potentially curative treatments*



*Palliative care is best delivered by interdisciplinary teams or clinicians*

*Palliative care can be given in hospital or at home*



## Key Steps for a Conversation to inform a family that death is expected and establish a plan of care

- Set up the conversation by introducing yourself and asking permission to proceed: **"Can I talk to you about what is happening to your loved one?"**
- Assess their understanding of the illness: **"What is your understanding of where your loved one is at with his/her illness?"**
- Share Prognosis: **"I wish it were different, but I am worried that your loved one is very sick and will not be able to recover from this illness. We do not have any treatments which can cure this problem and I am worried that he/she is not going to live for very long"**
- Assess goals and wishes: **"What are your goals, given the information I have shared with you?"**
- Establish plan: **"I recommend that we focus on providing care which ensures that she is comfortable, and she can be with those he loves."**
- Close the conversation: **"We will be here to treat and support your child and family."**

## Spiritual Concerns

- Parents were Muslim and an imam was able to visit them at home for support
- Mother wondered why god was punishing her in this way

## End of Life Care

- She received homecare for 3 months and died peacefully at home.
- The home care team provided weekly visits with emotional support, as well as providing symptom medicines and special foods

## Conclusions:

- Congenital heart disease is the **most frequent referral to palliative care via telemedicine** (34% of referrals).
- Palliative care is indicated in congenital heart disease when surgery is unavailable or not indicated.
- Home-based palliative care is a relatively simple and low-cost model to deliver palliative care, allowing patients to receive care at home, thereby reducing the burden on hospitals and families.
- Trained volunteers, and healthcare providers conduct home visits and provide telephone support, including advice about symptom management.
- This model has been implemented for refugees and the local population in India, Bangladesh and Uganda.
- Morphine is the first line treatment for shortness of breath in children.