Children’s Palliative Care Foundation
Inauguration
cum
Children’s Palliative Care Symposium 2018

Bereavement Support in Neonatal Intensive Care

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Neonatal Intensive Care Unit (NICU) is a place to.........
Change of parents’ expectation.....
Parents in a foreign world.............
Palliative care consists of three components

1. Pain and comfort management
2. Assist with end-of-life decision making
3. Bereavement support

(Romesberg, 2004)
The key roles of nurse in bereavement support are to:

- Establish a **good rapport** with the parents
- **Prepare the parents** to face their baby’s impending death
- **Pay attention** to critically ill infant and their parents
- **Help parents to plan** what they want to do for their baby when he/she is still alive
- Let the parents **fulfill** their parent role and try to **create** memorable moments for the family.

Kenner, Press and Ryan (2015)
The data of deceased in NICU of UCH

<table>
<thead>
<tr>
<th></th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>2016</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numbers of NICU admission</td>
<td>251</td>
<td>249</td>
<td>247</td>
<td>264</td>
<td>246</td>
</tr>
<tr>
<td>Numbers of deceased</td>
<td>7 (2.8%)</td>
<td>1 (0.4%)</td>
<td>5 (2.0%)</td>
<td>8 (3.0%)</td>
<td>6 (2.4%)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>• Hypoplastic lung disease (1) • E. Coli septicaemia with severe brain damage (2) • Hypoxic-ischemic encephalopathy (HIE) (1) • Severe intraventricular haemorrhage (IVH) (2) • Multiple Congenital abnormalities (1)</td>
<td>• HIE and Cyto-megalovirus infection (1)</td>
<td>• Hydrops fetalis (1) • Congenital Group B streptococcus (GBS) infection (1) • Necrotizing Entero-colitis (NEC) (1) • Hypoplastic lungs disease (1) • Severe IVH with pulmonary haemorrhage (1)</td>
<td>• Persistent Pulmonary Hypertension of Newborn (2) • GBS infection (2) • NEC of (2) • Multiple Congenital abnormalities (2)</td>
<td>• Hypoplastic heart disease (1) • GBS infection (2) • NEC (2) • E. Coli septicaemia with severe brain damage (1)</td>
</tr>
<tr>
<td>Length of Stay</td>
<td>1 day to 3 months</td>
<td>30 days</td>
<td>1 day to 4 months</td>
<td>2 to 37 days</td>
<td>1 days to 4 months</td>
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</tbody>
</table>
Bereavement Support Services in Paediatrics and Adolescent Department of United Christian Hospital

- Established in 1997
- A model of primary doctor and primary nurse to provide holistic family-centered care
- Inter-disciplinary team approach in daily operations
Our Goals of Bereavement Support are……..
The Framework of Bereavement Support in NICU of UCH

Phase I
Anticipatory Grief Management

Phase II
Last Journey of the Dying Baby with his/her Parents

Phase III
Follow up the Clustered Family & Funeral Issues

Phase IV
Refer Bereavement Counseling Service when in need

Lisle-Porter and Podruchny (2009)
A Story of Baby Lucy (1)

• In vitro fertilization (IVF) twins
• Baby Lucy and her sister were born at 24 weeks of gestational age with birth weight 600gm
• Her twin’s sister was 613gm
• After stabilization of twins, parents came to visit their tiny babies
• Interviewed by primary doctor and primary nurse
A Story of Baby Lucy (2)

• Baby Lucy with ventilator support after delivery and developed pulmonary haemorrhage on Day 3 of life

• Found to have progressive cerebellar haemorrhage on Day 4 due to failure control of bleeding

• Palliative care was initiated and interviewed with parents to discuss the plan of care
Phase I

Anticipatory Grief Management
Interview
Subsequent Interview with parents

• Continued to provide dignity and respect to parents and Baby Lucy
• Provided comfort care in life-limiting situation
End-of-life care plan for Baby Lucy

• Continue to receive pain-relieve medication intravenously
• Play the parent role
• Baby Lucy pass away in “beautiful look” in parents’ arms
• Family members can visit
• Pray with chaplain
• Continue to day-to-day assessment of Baby Lucy and parents
Decorate Baby Lucy’s bedside .....
Create precious moment.......
Initiate concrete memory......
Phase II
Last Journey of the Dying Baby Lucy with her Parents
A Story of Baby Lucy (3)

• She became deteriorating and poor control of critical condition with multi-organs failure.
• She was held in the arms of her loving parents and died peacefully on Day 7 of Life
Last office with parents ....

Mother tailor-made for her loved one
Let the parents and family say “Good-bye” to Baby Lucy

Provide privacy – preferable a quiet room with comfortable seats, warm water, and tissue
After saying “Good bye”, Baby Lucy ......
Collect memorable moments.....
Phase III
Follow up the Clustered Family & Funeral Issues
The choices of funeral arrangement
Parents chose hospital chapel for farewell Baby Lucy
Phase IV
Refer Bereavement Counseling Service when in need
Care of the carers

American Academy of Paediatrics Section on Hospice and Palliative Medicine and Committee on Hospital Care (2013) and Zhang & Lane (2013)
We integrate....... 

“Palliative care ≠ being abandoned”

“Incurable disease ≠ nothing more we can offer”
A Story of Baby Lucy (4)

• Unfortunately, twin sister was found a brain tumor and required chemotherapy

• Baby Lucy’s twin sister was discharged after 5 months of hospitalization

• Parents supported each other and they were facing this challenge positively
Look on the bright side.......
Summary

- **LISTEN** the parents **ACTIVELY**
- Identify the **NEED** and **PLAN** of period of pre-death, impending death and after death of infant
- Let the parents to have **CHOICES**
- Provide **QUALITY** experiences to parents
- Leave the family with something **POSITIVE** to hold on to
- Care of the **CARERS**
References


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