SIOP PODC Supportive Care Education Presentation Date: 9th January 2015

Role of Nursing in Supportive Care in LMIC

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- Presenters:
 - · Rehana Punjwani (Childrens Cancer Hospital, Karachi, Pakistan)
 - Glenn Mbah (Banso Baptist Hospital, Cameroon)
 - Karen Selwood (Alder Hey Childrens NHS Foundation Trust, Liverpool, UK)

Pakistan

Nurse Rehana Punjwani



Population 188 million

- Role of nurses in LMIC is very basic
- They are barely able to meet the physiological needs of the patients
 - Nurses are expected to only perform basic physiological care and assessment which includes
 - Vital signs, I/O, taking blood samples, patient hygiene

Challenges in Pakistan

- Overburdened nurses
 - Average nurse/patient ratio is 1:20
- Knowledge deficit
 - Nurses are not trained in childhood cancer care
 - Thus, they are unaware of the patients' supportive care needs
 - For example, the nurses have no knowledge about tumor lysis syndrome or hyperleukocytosis

Challenges in Pakistan

- Nurses have no autonomy
- Physicians are considered as first lead
 - Nurses are expected to follow physicians' orders without question
 - · Nurses are expected to be a physician's assistant
- Nurses are not allowed to discuss the child's disease, plan of treatment, or prognosis with the patient or family

Interviewed Nurses re: Supportive Care in Pakistan

- Nurses stated that they equate supportive care with palliative care
- All nurses wanted further education about supportive care
- All nurses stated they are prioritizing pain issues
- Almost all nurses stated that they hesitate to talk to patients and families about
 - Disease
 - Treatment
 - Prognosis

Action for Improvement -Pakistan

- The current nurse's role is very limited, but to increase the status of nursing, the first step is to provide nurses with the knowledge and and resources for providing supportive care.
 - Until they have the knowledge and resources they cannot provide holistic nursing care

Holistic Nursing

- A system of comprehensive or total patient care that considers the physical, emotional, social, economic, and spiritual needs of the person; his or her response to illness; and the effect of the illness on the ability to meet selfcare needs.
- Holistic nursing is the modern nursing practice that expresses this philosophy of care.

Communication in Pakistan

- Nurses lack the confidence to communicate with the patient or family due to a lack of understanding of childhood cancer and the effects of treatment.
- To involve them in patient/family education is not relevant until they are equipped with basic cancer knowledge.

In Summary - Pakistan

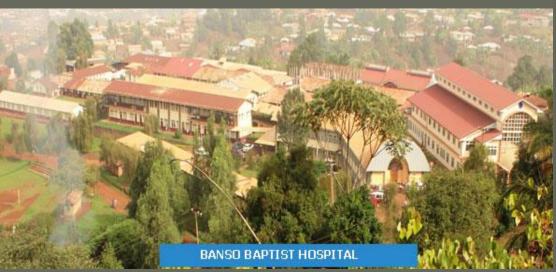
- It is not reasonable to expect that nurses in Pakistan caring for children with cancer can expand their role in supportive care without
 - Skills, knowledge and proper staffing

Introduction

Nurse Glenn Mbah







Psychological Adjustment

- Counselling:
 - Disease
 - Treatment goals and methods for patient and parents
 - Side effects
 - Fluid intake
 - Nutrition
 - Hygiene
 - Relapse and rescue
 - Treatment failure
 - Existential issues
- Repeated counselling as indications may occur
- Use of other professionals
 - Social workers, Nutrition counsellors, and Chaplains
- Play and other distractions for patients
- Creation and coordination of parent support groups

Counselling a Mother On Treatment Failure



Glenn Mbah

Nurse Practitioner: Vera Larfi Samba Epse Njamnshi

Pain and Distress

- Daily routine pain assessment
- Provision of 'STAT' doses of pain medication (without prescription) where necessary
- General anesthesia for Bone Marrow Aspirations (with nurse anesthetists)
- Morphine 30mins before L.P.s and wound care
- Distractions with games and movies
- Pain control at home

Tumor Lysis Syndrome Prevention

- Respect rate of N Saline infusion at 3L/m2/day
- Ensure adequate oral fluid intake after discontinuation of IV hydration
- Strict urine output and blood pressure monitoring
- Monitoring for signs of hyperkalemia, hypocalcemia, and renal failure
- Obtain blood samples for chemistry as needed
- Ensure allopurinol is taken as prescribed, and NaHCO₃ added to infusions as necessary

Nausea and Vomiting

- Anti-emetics: before and after chemotherapy
 - Usually oral Metoclopramide
 - For two days following chemo
 - May require I.M. Promethazine, and sometimes I.M Chlorpromazine.

Nutrition

- Fruits
- Avoid fats
- Oral rehydration solution
- Environment adjustment
 - Ensure ventilation
 - May move bed if neighbour incontinent of stool

Neutropenic Fever

- Hygiene
 - Daily bath, mouthcare, and bed-making
- Routine TPR checks every 4Hrs
- \bullet For any T \geq 38.5 $^{\circ}$ C
 - Explain to patient the possibility of neutropenia and sepsis
 - Immediate IV access, and sample collection for Malaria smear and CBC
 - First dose of antibiotics (Ampicillin and Gentamycin), if Malaria smear is negative.

Mucositis

- Daily observation of oral mucosa
- Administration of liquid analgesics
- Nutrition
 - Provision of soft(quasi-liquid) diet
 - F100 where necessary
 - NG tube where necessary
- Mouth care
 - Every 6Hrs
 - With hydrogen peroxide solution

Nutritional Support

- Rice and groundnuts
- Eggs and powdered milk daily
- Some money for purchase of fruits and other foods
- Special nutritional support for vomiting, neutropenia, and mucositis

Home Visits By Nurse

- To fetch patients who miss hospital appointments – abandonment
- Clear stigma on patient and family by explaining disease to neighbours
- For palliative care
- For establishing long-term status
- * Solicit advocacy by parents in their localities

Palliative Care

- Special nurse dedicated to palliative care
- Palliative care home visits
 - Pain medication refill
 - Management of other symptoms like vomiting, diarrhoea, constipation
 - Wound care
 - Spiritual care, with link to local pastors
 - Link to local health care workers and other social support systems



Challenges

- No dedicated doctor for child cancer unit
 - doctor shared with general paediatric ward
- One doctor on call for the entire hospital
- One dedicated nurse for child cancer ward
 - Backed up by Head Nurse of paediatrics and 1 palliative care outreach nurse for 2 hospitals
 - Same nurse responsible for data keeping and patient home visits
 - One shift for specialist nurse 07H 15H
 - Paediatrics ward nurses provide care for the rest of the day
 - Palliative care nurse and Paediatrics Ward Head Nurse cover during vacation
- Frequent change of Paediatrics Ward Head Nurse
- Language barrier in communicating with patients and parents

Points for Improving Supportive Care by Nurses

Nurses' availability

- On the ward
 - Need daily dedicated time to discuss patient and family concerns
 - Nursing rounds best opportunity for this
- On the phone
 - Odd hour calls may be burdensome for nurse, but can be reliable method to provide immediate relief or reassurance
- At patient's home
 - Home visits are essential when phone contact is impossible to determine reasons for missed appointments
 - Highly appreciated by families
- If home visits not possible
 - Use the peripheral health care providers in family's area for symptom management
 - Referral letters and phone contacts for local health care professionals is essential

Impacts of Recent Training from Utrecht University Summer School

Nursing care:

Introduction of a harmonised comprehensive daily patient monitoring form

Psychosocial care:

- Counselling of child on disease, treatment and side effects
- Introduction of HRQOL assessments with discussion sessions on every hospital visit

Pain prevention:

- Use of Morphine prior to L.P.s
- Blood collection done by experienced paediatrics ward nurses, instead of lab. staff

Nausea and vomiting:

- Round the clock anti-emetic for two days after chemo, instead of PRN
- Training of more nurses in chemotherapy administration
- Play and Learning:
 - Upcoming fundraising to construct outdoor playground and hire teacher for admitted patients



Nursing Role in Supportive Care in a High-Income Country

Nurse Karen Selwood Liverpool, UK



Population 64.1 million

- Designated oncology unit
- Nurses work as part of a Multidisciplinary team
- Team approach to care of the child and families – nurses are involved in discussions with families and participate in ward rounds
- Respect for everyone's roles and input

Supportive care in Liverpool

- Education of staff is ongoing depending on needs
 - all nursing staff trained in chemotherapy administration
- Basic nursing care is as important as more specialised care relating to the specific oncology needs e.g. hygiene, mouth care, nutrition
- 6 hospitals linked to us so families do not have to travel to the main centre for supportive care
 - these staff receive education around caring for the oncology children and there are link people to liaise with main centre.

Discussion

- Reactions to speakers' presentations?
- Ideas for improving nurses' role in supportive care in LMIC?
 - How to best provide education to nurses for delivering supportive care?
 - How to improve inclusion of nurses as autonomous team members with specialized skills?
 - How to broaden the scope of nursing practice to include competency in supportive care measures?