salutes all Pediatric Oncology Nurses

celebrating life while caring for children and adolescents with cancer

September 8, 2021

MAKING GLOBAL CONNECTIONS
Dear all,

As we continue to deal with the COVID-19 pandemic in our countries and work settings, we are also continuing to strive to provide the best care possible to our patients and families. What we do as nurses positively impacts our patients, and we know that the nurse-patient relationship also affects us in many ways.

In this issue of Making Global Connections, several pediatric oncology nursing colleagues share their stories of their most memorable patients. As pediatric oncology nurses, we have all encountered patients and families that have had a profound impact on us, which leaves a lasting impression or influence on our lives. We hope you enjoy hearing about these experiences and that this inspires you to recall your own most memorable patients.

As editors of the newsletter, we want to take this moment to acknowledge the dedication of the SIOP Global Health Nursing community globally as we celebrate Pediatric Hematology/Oncology Nurses’ Day on September 8th and Childhood Cancer Awareness Month throughout September. Thank you all, for all you do.

Linda Abramovitz
Liz Sniderman
Elianeth Kiteni
(Co-editors)
To our dear colleagues in SIOP Global Health Nursing,

2021 has continued to challenge us, both physically as we work tirelessly to fight against COVID-19 and to protect our most vulnerable patients, and mentally and emotionally as we are still unable to gather together as usual, to be with our patients, and in many cases, to provide the care that we are used to providing. As always, we find strength in each other and in our patients, and will find our way back to each other with more stories to tell, more ideas to share.

This year, we have continued to hold our monthly educational meetings to promote nursing professional development, and have been overwhelmed by the attendance and participation. We were honoured to jointly hold many of these sessions with other SIOP Global Health working groups, and plan to continue to do this in the coming years. Don’t forget to join us on social media and via WhatsApp where you will hear of upcoming meetings, opportunities, and celebrations of each other’s successes.

Facebook: SIOP PODC Nursing
Twitter: @SIOPpodcNursing
WhatsApp: (join via QR code)

You will also notice that SIOP PODC (Pediatric Oncology in Developing Countries) has officially undergone a name change: we are now SIOP Global Health, which better reflects the global nature of our collaborations, and phases out the use of outdated terminology. We hope to see many of you at the upcoming virtual SIOP Congress on October 21-24, 2021. Following the Congress, we will hold a SIOP Global Health Nursing meeting to plan our priorities and educational sessions for the upcoming year, as well as announce the rotation of the co-chairs.

Liz Sniderman and Yuliana Hanaratri
SIOP Global Health Nursing Co-chairs
Patients and families are at the heart of our work as pediatric oncology nurses. Below, read stories of memorable patients that have had a profound impact on nurses from Uganda, Vietnam, Australia, and Indonesia

"My Independence Day Girl"

Noor Siti Noviani Indah Sari
Rumah Sakit Kanker Dharmais | Jakarta, Indonesia

Every year, in my country, Indonesia, we always celebrate Independence Day which falls on 17 August. Usually on that date, the people of Indonesia celebrate various simple and interesting competitions. The children and some parents participate in the various competitions, and they are happy together. However, when children with cancer have to be treated and stay for a long time in the hospital, they will miss this moment. Not only the children who feel lost, but the parents also lose their time to relax, gather and participate in competitions with other parents in their neighborhood.

For this reason, since 2015, the nurses in our unit have tried to hold a simple competition for children and parents. Usually we choose a simple and an easy one for the children, so that they are not too tired after the race. The competitions are usually coloring a picture and fashion shows of traditional clothes from various regions in Indonesia. There is also a “proper handwashing” competition for parents.

Among the patients who had participated in the competition, there was a beautiful girl named Jesiska. She is one of the children with Acute Lymphoblastic Leukemia (ALL). Sometimes, she entertains friends who are in the same age or younger than her, so they can get through the early and difficult phase of chemotherapy. Jesiska also gets along well with the nurses, doctors, and staff at the hospital. No wonder that everyone knows about Jesiska and her family. Her enthusiasm to recover and go back to school made Jesiska strong through the stages of chemotherapy.
However, in the last evaluation, her Bone Marrow aspiration results showed that Jessica had relapsed leukemia. She has to again undergo a long series of chemotherapy treatments and blood transfusions due to a decrease in several components of blood cells in her body. Sometimes she looks pale and weak. Sometimes she feels pain in her head or all over her body, and she cries. But she got over it and got cheerful again. When she was going to be put on an IV for chemotherapy, Jesiska could still joke around, and sometimes she didn’t pay attention to the pain.

On the 17 August 2017, Jesiska was still enthusiastic about participating in the competition. Her body was starting to get weak, but Jesiska had the spirit to compete. For that reason, the traditional fashion show competition was chosen for Jesiska. Jesiska walked beautifully and there was a gleam of happiness and pride in her beautiful eyes. With Balinese dress, Jesiska looked beautiful at the fashion show. Even though she looks weak, when she walks on fashion show competition, Jessica looks very strong and enthusiastic. It showed as if she was saying, “I will be strong and eager to defeat this leukemia. I am a warrior who beats cancer, like the Heroes who beat the enemy. I am the fighter against cancer, the dreaded villain of the disease.”

Unfortunately, Jesiska’s struggle was over. Jesiska "must return" to God. Jesiska passed away on December 2017, a few months after the August 17 race had ended. However, Jesiska’s spirit and joy will always remain in our hearts at the Dharmais Cancer Hospital. Jesiska became an icon among pediatric nurses as a formidable fighter against cancer.

Goodbye, Jesiska. You are a tough warrior girl. You will be always our "Independence Day Girl".

Jesiska in her Balinese clothes during the fashion show competition August 17th
My Most Memorable Patient

Rose Nankinga
Uganda Cancer Institute | Kampala, Uganda

My name is Rose Nankinga, a Senior Pediatric Oncology Nurse working at the outpatient department of the Uganda Cancer Institute in Uganda.

The patient I wish to share is a 12-year-old girl who was diagnosed with Pinealoblastoma in 2016, who underwent chemotherapy treatments. Her mother deferred treatment with radiotherapy. From the time of admission to date, we are very close buddies. Unfortunately, because she did not get local control, she suffered a relapse that almost claimed her life in 2018.

We, the clinical team and her family were scared of the outcome since she was very sick. During her stay in hospital, she always wanted to know that I’m around, and that she could confide in me. She always asked for nurse Rose to get a venous access, to feed her, to be by her side, and to talk to her always. Even at home she would call, and we chat, I would convince her to take her meds and sing or play with her.

She's doing well and is free of disease now and tells me never to call her a cancer patient. She will only show up after calling and making sure I’m present at the clinic. When she’s around, we move around looking for small babies because she loves them so much and also practices becoming a nurse by demonstrating how to give injections!

There is so much to share about this angel. May God keep her cancer free and may the family enjoy their only girl. I never thought that I would be so dear to a patient and their family.

“From the time of admission to date, we are very close buddies... I never thought that I would be so dear to a patient and their family.
My Patient: "M"

Zahra Faisal Moh'd Ahmed
Sydney Children's Hospital | Sydney, Australia

My most memorable patient was M, I met her in my new graduate year of nursing and 8 years later she is the reason I have continued to stay in nursing. Whenever I start to feel overwhelmed, burnt out or not good enough at my job, I think of this beautiful 17-year-old girl who reminded me that my job was more than doing tasks. M was diagnosed with Acute Lymphoblastic Leukemia when she was 16 years old, I looked after M for almost two years of her treatment, and I was fortunate enough to watch her graduate high school. M inspired me to be fearless and to trust in my ability. I was a novice in my career, and I felt incompetent compared to my senior colleagues. Every task seemed daunting, I struggled with fitting in and dealing with all the information that I needed to learn. M taught me to trust my instincts and to believe in my nursing ability. I had conversations with M about losing her hair, not being able to do things with her friends and body image issues. Nursing was more than how many medications you give, how knowledgeable you sounded and how confident you were. It is easy to get caught up in the politics at work, the negative self-talk and even the blame game but the reward of helping a family navigate devastating diagnosis is far greater.

There were many tears and frustration between M's family, I was able to listen and hold M's hand during a difficult period in her life. Even though I struggled with finding my way in a fast-paced environment, I was able to be a good listener and be empathetic to a teenage girl that was fighting for her life. I was able to grow in my confidence by providing compassion, empathy, and a safe place for my patient to share. I held M's hand when she was going through a panic attack at 2 am, I still remember her mother's face when she ran out to get help. I will never forget the simple act of not saying anything but staying by her bedside and letting her cry until she fell asleep.

A patient's mother recently reminded me that the nursing profession is a calling, it is about helping a child and their family get through a difficult time. I hope this can inspire someone that needed a reminder that by helping just one person, you can make a world of difference in their lives. We can easily get caught up with the pressures of feeling like we aren't doing enough, but it's the small differences we make that go a long way. I studied and trained in Canada; I had always dreamt about working as a paediatric nurse abroad. On my last shift, M gifted me with this mug, and I've brought it with me to New Zealand and Australia. This mug is a reminder that tasks can be done anytime, your presence and support is much more valuable.

P.S. I always laugh at the spelling error of patients and patience – maybe she was on to something.
My name's Hoang Thi Ai Tram, I have been working at the Transplantation Unit at Hue Central Hospital, Vietnam since November 2019. Up to now, I have taken care of 13 patients and each patient has brought different emotions to me. The common theme is that the patient was healthy and discharged successfully.

The patient that had a profound impact on me was a patient with metastatic retinoblastoma. She is a 3 year old girl. She is so clever, courageous and lovely. At her age, she could speak two languages: Vietnamese, and an ethnic language. With the conditioning regimen with thiotepa, she had severe diarrhea and vomiting. She experienced septic shock. At that time, I was so worried. But with the help from doctors, other nurses, and her efforts, she overcame successfully. When she was tired, she could not talk, but she was so clever to express with her body languages and always obeyed my directions. She inspired me significantly and reminded how precious life is and how important teamwork is!

When she recovered, she was so happy and talked with me a lot. I really love her and love my work. I promise to try my best to save more children.

Photos used with permission of patient’s parents
ABOUT THE CONGRESS

Experience 4 outstanding days of cutting-edge science, engaging debates and networking with world-renowned experts at SIOP 2021!
Advance your paediatric oncology career, connect with like-minded people and contribute to a world where no child should die of cancer!

The Congress programme will be running on Eastern Standard Time (UTC-5). If you cannot join a session live, you can watch its recording afterwards.

VIEW THE PROGRAMME:
https://siop-congress.org/programme/

REGISTER TODAY!!
https://siop-congress.org/register/
recordings available on CancerPOINTE

https://cancerpointe.com/siop-podc-nursing-meetings/

- Global Perspectives on Supportive Care after BMT
- Burnout in Pediatric Oncology Nurses
- Treatment Engagement and Communication between Parents, Nurses and Other Providers
- Traditional and Complementary Medicine In Pediatric Oncology: What Nurses Need to Know
- Safe Chemotherapy Handling Updates for Nurses
- Pediatric Palliative Care in the Home Setting in LMICs: Challenges and Solutions
- Family Centered Care in Pediatric Oncology
Happy Pediatric Oncology Nurses Day 2021!

In celebration of September 8, 2021, Pediatric Oncology Nurses Day, a the SIOP Global Health Nursing Working Group created a poster to celebrate the work of pediatric oncology nurses.

This poster is available to download in 22 languages on the SIOP Website: https://siop-online.org/news/pediatric-oncology-nursing-day/

With special thanks to those who helped design and translate this poster

https://siop-online.org/news/pediatric-oncology-nursing-day/
GET INVOLVED!

The SIOP Global Health Nursing committee collaborates regularly with other SIOP groups, and encourages our members to do the same. See below for opportunities for involvement and to have your voice heard.

1 Contribute to the newsletter

If you are interested in disseminating nurses’ stories from around the world, as well as sharing your own stories, we are looking for submissions for the Making Global Connections Newsletter, as well as those interested in becoming an editor. Please email bmtskier@comcast.net or liz.sniderman@stjude.org for more information!

2 Join other Global Health Working Groups

Nurses are welcome and encouraged to join other Global Health Working Groups to learn, collaborate, and share the nursing perspective with multidisciplinary colleagues. Search for the other Global Health groups on Cure4Kids and "request to join"!

3 Share your knowledge: be a speaker!

SIOP Global Health Nursing invites its members to share your specialty knowledge as a speaker at a monthly educational session. Contact the co-chairs if you would like to be a speaker.

Also, don’t forget to start collecting data now for next year’s abstract submission!
GOLD SEPTEMBER IS
CHILDHOOD CANCER AWARENESS MONTH
#TURNGOLDSIOP

MERIN, AGE 6
LOW GRADE GLIOMA SURVIVOR & FUTURE LAB ASSISTANT

CONTACT US!

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