

# The Portrait of a Dying Child

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## Abstract

The portrait of a dying child is an homage to a child's journey from initial diagnosis to the terminal stages of illness in metastatic neuroblastoma, raising the critical question of the importance of defining a beautiful death – a concept I first came across as a literature student in Henrik Ibsen's renowned tragedy *Hedda Gabler*. In this article, we discuss a case study of a child named Peter (real names have been changed to maintain the confidentiality of the patient) and his family, whom I met during my oncology rotation as a junior pediatric resident, and various aspects of care – ranging from symptom management, pain control, the family as an emotional and spiritual unit and complications of metastatic disease. Interlaced amidst references of current practices related to pain control and palliation of symptoms are quotes from Dr Myra BluebondLangner's books and a personal encounter with the child to construct the child as a child and not another dying patient. The enigma of the definition of a beautiful death is also discussed from the patient and the family's point of view. An ideal medical death would be one without pain and with optimal symptom control; however, a beautiful death is so much more – encompassing a peaceful passing surrounded not by machines but by happiness around and at heart. We hope this article would encourage pediatricians to continue to practice pediatric palliative care in the daily setting when dealing with critically ill patients or children in their final stages of life.

**Keywords:** Oncology, paediatric, palliative care

## THE PORTRAIT OF A DYING CHILD

Back in my school days in literature class, we studied the famous Norwegian playwright Henrik Ibsen's critically acclaimed play *Hedda Gabler*. The recurrent theme of dying a beautiful death is emphasized by the protagonist Hedda throughout the entire play. I remember my teacher belting out the words "Her idea of a beautiful death was synonymous to an act of liberation."

Many years later, as a second year paediatric resident, the phrase 'beautiful death' echoes in my mind as I am faced with the pertinent question which plagues the world of paediatric palliative care: what is a beautiful death for a child?

"All of the leukaemic children whom I studied faced death with a great deal of understanding about the world of the seriously ill and their place in it. They knew the institution and the diseases as well as any lay adult."<sup>[1]</sup>

– "The Private Worlds of Dying Children", Dr Myra Bluebond-Langner

I chanced upon these words while reading Dr Bluebond-Langner's book on my way to Great Ormond Street Hospital from Crouch End as a 4<sup>th</sup> year medical student. No matter how young a child

is, the child realizes when they are in their terminal phase of life not only secondary to disease progression but also due to the change in the reactions, the emotions and the environment around them, a phenomenon Dr Bluebond-Langner observed in her time. The children of her time are no different from the children of the present.

When I did my rounds that morning, we saw a child with leukemia in his final stages of life. The many lines-central and peripheral, the pallor, the distended abdomen, the skin metastases, the faint glimmer of life that barely peeked through his eyes which were heavily sedated and the gasps of air, clamoring for life which was slowly ebbing away. His mother was holding his hand, warming it up, hoping to bring a little color back. That day, my mind captured the portrait of a dying child and until today, the image remains embedded in a memory that replayed itself all too soon...

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A 6-year, 2-month old Chinese boy is from the little town of Ipoh, Malaysia. He first presented with abdominal distension which progressed to abdominal pain associated with pallor and fever when he was 5 years old. A computed tomography (CT) scan was done in Ipoh revealed a large abdominal mass. His parents sought a second opinion at our hospital in Singapore where a laparoscopic guided biopsy of the mass was performed. Intraoperative findings revealed a right suprarenal tumor invading into the right lobe of liver. Histology taken confirmed the diagnosis of undifferentiated neuroblastoma with no N-MYC amplification (a poor prognostic marker) and deletion studies for 1p and 11q were inconclusive. Sampling of the peritoneal fluid showed no malignant cells. Metaiodobenzylguanidine (MIBG) showed a large right adrenal mass with MIBG-avid retro-peritoneal lymph nodes and right hepatic metastasis. MIBG-avid bone metastasis was also seen in the right ilium which was consistent with the initial bone scan done which demonstrated increased tracer uptake in the right iliac bone. A bone marrow aspiration (BMA) revealed metastatic infiltration. In view of metastasis to the bone, marrow, and liver, this was a Stage 4 neuroblastoma.

Peter was started on the modified N7 protocol in which induction chemotherapy comprised of 5 cycles of alternating the combinations of cyclophosphamide/adriamycin/vincristine and cisplatin/etoposide.<sup>[2]</sup> After completing four cycles of chemotherapy, interval scans performed showed a significant interval decrease in the size of the lobulated right adrenal mass and a decrease in the size of nodular foci in the right hepatic lobe. There was also significant interval improvement noted in the previously enlarged and confluent retroperitoneal lymph nodes. A repeat BMA was negative for metastasis. In view of the interval improvement, his parents refused further treatment and returned to Ipoh as they did not wish for their child to undergo surgery in view of his young age.

It was not soon after when they returned in March 2017, after the child's last chemotherapy in June 2016 and defaulting subsequent follow-up treatments, when he presented with bone pain. A positron emission tomography (PET) scan done in Ipoh confirmed disease progression. His family returned to Singapore where further imaging here showed the progression of liver and adrenal metastasis. He was then started on salvage chemotherapy with cyclophosphamide, topotecan, and vincristine. After two cycles, a hepatobiliary ultrasound showed continued disease progression. Hence, he was switched to third-line therapy with Irinotecan and Temozolomide, of which he received two courses.

As a pediatric resident rotating through the ward, I first met the boy and his family when he was electively admitted for a repeat PET-CT scan after he received the second course of Irinotecan and Temozolomide. I met a cheerful, vibrant child who was busy doodling and coloring. He had a bit of a temper but he still smiled at me whenever I greeted him. His parents were hopeful although his primary oncologist was worried that he was running out of time.

## COMPLICATIONS OF THE METASTATIC DISEASE

### Cord compression

The fludeoxyglucose (FDG)-PET CT showed that the retroperitoneal lymph nodes were larger, there were new FDG-avid lesions in the liver and multiple foci of uptake in the bones suspicious for bony metastases. There was also moderate stenosis of the spinal canal at T5 and T8, raising the concern of cord compression. Although he did not have any neurological deficits and his bowel and bladder function were intact, an urgent neurosurgery referral was made and a magnetic resonance imaging (MRI) of the spine was arranged.

He was started on intravenous (IV) dexamethasone. The MRI of the spine showed a pathological compression fracture at T5 and metastatic involvement of extravertebral soft-tissue components at T5 and T8 indenting the thoracic cord. Arrangements for palliative spinal radiotherapy were made.

### Tumor rupture

He was readmitted for abdominal pain a few days later. When I entered the ward, there was a child screaming in pain. This was not the same child whom I saw the last time. He was uncomfortable. He was cross with his parents. His abdomen was significantly distended with firm hepatomegaly. An ultrasound abdomen done initially did not show the evidence of intussusception or any abnormality beyond hepatomegaly. However, a couple of days later, when he returned from his session of palliative radiotherapy, he appeared as pale as a sheet and was lethargic. A complete blood count showed a hemoglobin level of 6.3 g/dL. An urgent bedside ultrasound revealed a significant interval increase in free fluid noted in all four quadrants of the abdomen and the pelvis, suspicious of a hemoperitoneum. He was immediately transfused with 2 units of blood and given a dose of Vitamin K.

It was a near death situation, and his 10-year-old sister came that night as his parents were afraid that he would pass on that night itself.

“The well siblings” views are connected to their experiences. Central among these experiences are their parents’ responses to the care the ill child requires and the concerns the child’s condition engenders. Their views are part of an interpretative process that involves both the parents’ and the ill child’s condition”<sup>[3]</sup>

– “In the Shadow of Illness”, Dr Myra Bluebond-Langner

That night, his older sister, who was an absent figure till that moment, appeared, to give her dear brother a hug as she somehow realized, in her 10 years old mind, her time with her younger brother was short.

A repeat blood count after the transfusion showed an improved hemoglobin level of 10.1 g/dL; however, he was screaming again.

## PAIN CONTROL

A referral was made to the palliative team and the pain team. The pain team managed the abdominal pain with an initial morphine infusion and breakthrough bolus which did not work. Upward titration of the morphine dosage then resulted in episodes of acute urinary retention and constipation. As his pain was not well-controlled, the pain team decided to change their choice of opioids to fentanyl with a combination of ketamine, both as infusions with breakthrough boluses administered by nurse controlled analgesia. Unfortunately, every time we entered the ward, we heard the poor child screaming in pain.

The pain team then added gabapentin to help manage the neuropathic pain that was possibly originating from the indentation of thoracic cord by the extravertebral soft-tissue metastases.

There was gradual escalation of opioids as per the World Health Organization Pain Ladder.

The analgesia that worked best for this child was methadone, which has 2.5–20 times more analgesic effect than morphine. With its high oral bioavailability and an analgesic effect which starts earlier,<sup>[4]</sup> the child felt better and stopped screaming. He could sleep more comfortably uninterrupted and when he was awake, he would be watching the Disney cartoons. Improved pain control was also demonstrated in him permitting physical examination of his abdomen and in his improved moods.

In children with life-limiting illnesses, the use of high doses of opioids for pain control has to be balanced against potential side effects, and currently, the pain control regimens are based very much on adult pain control regimens. Hence, in this case study, there was always a debate between increasing the strength of opioids to higher doses or changing it to a stronger opioid and balancing the side effects as well. Thankfully, this child did not show any significant side effects such as respiratory depression, acute urinary retention, or constipation when he was on methadone, clonidine, and gabapentin.

As the days passed, I grew closer to the parents of Peter. One morning, I asked his parents about his favorite toys and they mentioned that he loved Lego. My colleague bought him a Lego set and we decided to surprise him one morning.

Me: My dear do you still have tummy pain?

Peter (screaming in pain, although I was not examining him): Yes!

Me (brings out a Lego toy set with my colleagues): Will Lego make the pain go away?

Peter (stops screaming and looks curiously at the Lego toy set): Nods head Me: Shall I place it here by your side?

Peter (now no longer in pain and comfortably tracking the Lego toy set): Ok

We gently placed the Lego set by his side, his eyes fixated on the set even though he had developed a left lower motor neuron facial nerve palsy (possibly secondary to brain metastases

which is common in relapsed neuroblastoma patients.<sup>[5]</sup> His parents were not keen for further investigations at this point unless he became symptomatic, but he did not have signs of raised intracranial pressure such as headache or early morning vomiting) and he stopped screaming.

He carefully analyzed the three of us who were standing by his bedside. With this simple gesture, we were now on his side, a phenomenon that Dr Bluebond-Langner also describes in her book. Children dichotomized the people they met – those who were the “meanies” who would be doing procedures on them and those who “protected” and “nurtured” them.

This incident also taught us and the pain team that his pain was not entirely somatic. With liver metastases, the distension of the liver capsule, and the compression of the primary adrenal tumor on surrounding organs would undeniably result in pain, but this incident highlighted that his pain was distractible. There was an element of psychological distress probably in anticipation of pain which may not be there all the time.

We introduced an art therapist for him as well who colored circles and showed him. He was too weak to color on his own at this point, but he would patiently observe the art therapist coloring away.

Children at his age are not emotionally mature enough to separate the physical and emotional nature of suffering. They may develop anxiety which may manifest in different expressions such as screaming in this child’s case. The anxiety may be a result of anticipated pain or nonresponsiveness to therapy which always needs constant reevaluation by the multidisciplinary team.<sup>[6]</sup>

## SYMPTOM CONTROL

Often, children, in their terminal stages of life, have symptoms such as nausea and vomiting secondary to pain, anxiety, or use of opioids. Beyond systemic analgesics, he was given antiemetics. Palliative radiotherapy was administered to the spinal metastasis to prevent the progression of cord compression, to minimize the potential for symptoms of lower limb paralysis and loss of sphincteric control. He also received palliative radiotherapy to his abdomen for pain control. Palliative radiotherapy is well-studied to help with pain control for liver and bone metastases though there are few studies which discuss its efficacy for brain metastases.<sup>[7]</sup>

Following his acute tumor rupture, full blood counts were closely monitored for a week and found to be stable. He also developed fever during his admission which could have been contributed by the underlying malignancy. IV broad-spectrum antibiotics were given till his fever settled and cultures returned to be negative.

For his left facial nerve palsy, eye drops were applied to the left eye in view of incomplete eye closure on blinking to prevent exposure keratitis. Invasive procedures were otherwise minimized.

The palliative team also ensured that his nutrition was taken care of that he had adequate urine output and bowel output every day. These are the basic activities of daily living a child would like to be able to continue to do as it restores a sense of “normalcy” and reassures the parents that their child is comfortable even in the final stages.

## THE FAMILY

When his pain was still not optimally controlled with ongoing titration of analgesia, extended family members poured in from all over to visit Peter. There was grief. His parents were initially upset the pain was not well controlled. There was uncertainty. However, there was an element of spirituality with the family using religious ornaments on him (a tiny yellow cloth they pinned to his hospital attire), and they fed him a special herbal juice (which they believed to possess curative powers). They also believed in creating a sphere of positive energy around him by asking the palliative team not to openly discuss death in front of him and to always use analogies of other children dying instead of using their own son.

They agreed with the Do-Not-Resuscitate order when their child was clinically unwell at the point of tumor rupture and indicated they preferred for him to pass on at home. Our local palliative team had contacted and made arrangements with the palliative team at Ipoh and before I completed my rotation, they had plans for him to head home to Ipoh once the pain was well controlled.

Managing the family’s needs is pivotal when managing a pediatric palliative patient because it helps to ensure that reasonable expectations are set and that everyone is on the same page. Long-term support is also required regarding bereavement which comes in many stages. This support is usually mostly from the family lattice but can also come from the medical team and the allied healthcare staff.<sup>[8]</sup>

It is also important to have a family conference with the multidisciplinary team at different stages throughout the progression of the child’s illness so as to pre-empt unforeseen circumstances or to ensure that the family’s wishes are respected. After the main family conference was held at the beginning of the admission with the primary oncologist, a subsequent one was held to offer the parents alternative options if they do not make it back to their hometown Ipoh in time such as the local hospice and explored options in towns closer to Singapore such as Johor which was a 2 h drive from Singapore as compared to Ipoh which was a 5 h drive away.

The reality of the child passing on suddenly in the hospital was also highlighted, and the site of burial was broached by the palliative team, and the parents agreed for him to be cremated and for his ashes to be transported back to Ipoh should he pass on locally.

Interestingly, an advanced care plan was not drawn up for this family due to the rapid progression of events. The main barrier was also parents not wanting the palliative team to

broach the topic of death with the child and still wanting to create a positive sphere of energy around the child which is understandable as any parent would in their shoes.

On a more practical note, financial support is a key factor. They had financial constraints and were not eligible for subsidies reserved for locals. It is important to address these practical issues early on as well to help the family in a holistic manner.<sup>[9]</sup>

I was very grateful to this gracious family who were resilient and who put up a brave front for their child. There were nights when I would see them crying by the bedside when I was the resident on call. It was difficult for them but offering them a pat on the back and checking in on them did help them feel better (in what little way it could).

## THE PORTRAIT OF A DYING CHILD

When a child is in his final stages of life, a child knows. His parents start giving in to all his requests. He gets everything he wants. This scenario was no different. When I left the ward, I remember a child who was more comfortable. However, he still had a left facial nerve palsy, many lines, both central and peripheral, a distended abdomen, significant peripheral edema (scrotal and lower limbs), bone pain around his hips and knees, but he was calmly watching his Disney shows and he carefully observed me – the quiet, invisible friend he had made through the many nights I had visited him while I was the resident on call as well as my daily oncology ward rounds. It also made me ponder about his comprehension of death.

Many a times, when his abdominal pain was initially unbearable – I remember standing helplessly by his bedside when he would yell “Please make it stop. I don’t want this anymore! I don’t want this anymore!” He would then go on to ask “Why Daddy? Why does my tummy hurt so badly? Please make it stop.” When young children are in their final stages, I have noticed from my experiences that they begin to ask more thought-provoking questions – very much like adults. This always seemed unusual to me, but sometimes I wonder if this is a sign that the children have gained some degree of maturity, enough for them to realize that their end is near.

At the age of six, a child begins to form concrete thoughts. They are more truthful and they begin to understand concepts such as death. Peter was also still needing his parents by the bedside, holding onto them for courage and strength.<sup>[10]</sup> Whenever I interacted with him, I always asked if he was okay and if his parents were okay. We built the connection through our Lego, my indirect gesture of making sure he was happy. I never once spoke to him or the family about dying or death because I felt that they knew, they were ready and they had accepted it deep inside. When I say “they”, I refer to the child and his parents.

The dying child is still a child – a child who loves to play, to draw, to color, to watch cartoons and to do everything any other child would like to do. There is a spectrum in the category of



a dying child. The child with leukemia I described earlier on was in his final stages while this child with neuroblastoma has a terminal illness but is still pressing on for reasons beyond comprehension that even medicine can't answer. But each child, dying or not, deserves the same degree of respect and love any child deserves.

“When one does such research, contributions to science are not sufficient justification, in my view. I have failed unless this study contributes to the memory of the children, to those who cared for them, and to children who still must suffer.”<sup>[1]</sup>

– ‘The Private Worlds of Dying Children’, Dr Myra Bluebond-Langner

I vividly recall the humble closing words to Dr Bluebond-Langner's ode to pediatric palliative care. By sharing the case study of Peter, I hope to share the importance of the managing a dying child with a multipronged approach ranging from the medical management of the primary tumor, to pain control and symptom management to management of the family and ultimately, the psychological needs of the child.

The portrait of a dying child is written in honor of all children who, as Dr Bluebond-Langner highlighted, “still must suffer.” My wish is with the advent of pediatric palliative care, these children will have a more peaceful passing and a “beautiful death” so that these children will 1 day be finally free of all pain and free of all suffering.

As for Peter, I hope he reaches his childhood home in the little town of Ipoh in time where he can spend his final moments with family and loved ones.

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There are no conflicts of interest.

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