

By Dr Grace Pang

Dying Young

“You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.”

– Dame Cicely Saunders,
founder of the modern hospice movement



Dr Grace Pang is presently a lab rat trying to figure out (not very successfully so far) the genetics of emesis. Despite her rattiness, the care of dying patients is a subject that is very close to her heart and mind.

The death of a child is one of the most sorrowful tragedies that can afflict a person. Despite advances in medical science, the sad reality is that children can still die after all attempts to cure them. Unfortunately, the growth and development of paediatric palliative services have not paralleled that of adults. But children matter too. They matter to the last moment of their life. It is our duty as professionals and as human beings to ensure that their last moments are peaceful, and to help them live until they die.

THE DYING CHILD

How big is the problem?

One of the most quoted studies was conducted by Wolfe et al at the Boston Children's Hospital and published in the *New England Journal of Medicine* in 2000. This study showed that a large proportion of dying children suffered many

symptoms ranging from pain to lethargy. These were often under-diagnosed or under-treated by healthcare professionals. Although there have been other studies with similar findings, it was gratifying to see a study highlighting the plight of dying children published in a high impact journal.

Who are these children?

They can be grouped into four categories according to Goldman's classification:

- Children with conditions where potentially curative treatment has failed (for example, malignancy);
- Children with conditions where intensive treatment may prolong life but premature death occurs (for example, cystic fibrosis);
- Children with progressive conditions where treatment is exclusively palliative (for example, Duchenne muscular dystrophy); and

- Children with non-progressive neurological conditions, which result in an increased susceptibility to complications and premature death (for example, cerebral palsy).

Unlike adults who are dying, the prognoses of certain categories tend to be more uncertain. As medical science advances, some of these children who would have previously died in childhood can now live up to young adulthood.

“I only want what is in your mind and in your heart.”

- David Tasma, as he neared the end of his life to Dame Cicely Saunders.

Symptoms such as pain and lethargy are highly prevalent in dying children. Sadly, they are often undiagnosed or under-treated, causing distress and suffering to the dying child. Caring for dying children is not just about holding their hand sympathetically as they scream in pain. Dying children deserve more. They deserve the use of our professional knowledge and advances in medicine to treat their symptoms and enhance their quality of life when the main goal of care changes from cure to comfort. They need skilled nursing and medical care as their frail bodies weaken and become increasingly dependent as well as disabled. Poorly controlled symptoms do not allow dying children to live until they die.

It is important and reassuring to note that many of these symptoms can be managed by any practising doctor. However, in a certain proportion of cases with complex symptoms, it would be preferable to refer the child to a palliative care physician.

THE LAST DAYS

One of the barriers to the provision of paediatric palliative care is the inability of healthcare professionals to acknowledge that this child is dying. As professionals, it is important to be able to recognise dying, for it helps us to put our management goals into perspective as we prick the crying child for the nth time to do routine blood investigations that often yield little information that alters treatment or

improves quality of life. Conversely, healthcare professionals must acknowledge that being labelled as terminal and incurable should not exclude the dying child from the latest medical advances that are able to improve quality of life and perhaps even extend lifespan significantly without causing too much distress and suffering.

“Even though I walk through the valley of the shadow of death,
I will fear no evil, for You are with me;
Your rod and your staff,

- Psalm 23

Journeying through the valley of death with the dying child and the family is one of the principle tenets of paediatric palliative care. We are not just treating the disease. We also have to treat the child with the disease and the people surrounding the child with the disease. The cerebral hard science of medicine needs to be married with the unconditional love and tenderness that only the human heart can give.

Symptoms that cause distress and suffering are not the only burden that children and their loved ones have to bear. They also have to wander through an emotional minefield as they grapple with the imminent real possibility that this young life will one day be no more.

“I’LL ALWAYS LOVE YOU”

Good communication skills are essential in this journey with the dying child and family. Communication is not confined to comforting words but also encompasses touch and listening. A simple gesture, such as holding a person’s hand, speaks a thousand words. Listening to what our patients have to tell us is rare in our busy lives. We often do not listen to what the dying child has to tell us for various reasons, including our misguided belief that a child cannot understand the meaning of death, or that a child can have opinions and wishes about what he or she wants in life. Studies indicate that children have some concept of death from as young as 4 years old. Children are human beings with the capacity to feel, think and decide within their level of intellectual development and emotional maturity. They can have such insight and maturity

about subjects that adults often feel uncomfortable discussing. One of the most moving words that I have heard as a hospice doctor came from a child who told her parents as she neared the end her life, “Whatever happens to me, I’ll always love you.”

Listening allows us to know when and how to discuss sensitive topics, such as dying, at the appropriate time and in the appropriate manner. Being able to empathise and establish goals of care with our young patients and families can only come after listening receptively and understanding fully what they have to tell us.

Understanding the psychosocial cum spiritual dynamics of dying children and their families helps us to understand their behaviour and responses, some of which can be difficult for healthcare professionals to cope with. Accepting the tragic reality that their child is dying is a process that has to be dealt with by the child and family in their time, on their terms – and not our time or our terms.

Healthcare professionals need to acknowledge that children, just like adults, need the space to be themselves and that they have physical, spiritual and psychological needs that can only be fully addressed by a professional multi-disciplinary team caring for them from diagnosis to death, as indicated in the statements on paediatric palliative care from WHO, the American Academy of Paediatricians, and the Royal College of Paediatricians.

THE PROFESSIONALS

What are the other needs of dying children?

These can be classified into four areas: research, education, staffing and funding.

Good research is necessary for a good clinical service. We need to identify areas in the care of dying children that are lacking in Singapore as well as audit existing services to raise the standard of care. Understanding the science of dying and employing evidence-based medicine appropriately enables healthcare professionals to better manage the dying child.

Educating healthcare professionals and the public of a taboo subject, such as death and especially dying children, is never easy. Nevertheless, it needs to be done. There is a need to know of the existence of the palliative care services that are available to children and families facing a life-threatening disease. Teaching healthcare professionals how to manage common symptoms in dying children and when to refer for specialist palliative care consultation, as well as good communication skills, is part of a good training programme in general medicine.

The lack of trained staff has always been a bugbear for palliative care providers and even more so in the field of paediatric palliative care. The lack of a structured career path combined with the perception that it is a depressing branch of medicine where there are more downs than ups in patient outcome attracts few healthcare professionals to join it. There are no quick and easy solutions to remedy these problems.

I can only delve into my personal experiences in caring for the dying, and say to readers that being able to give all that I can as a professional and as a person, to patients at the end of their lives as well as to their families, has been immensely enriching. It somehow compensates for the ‘ups and downs’ that we face in this field.

However, the care of the dying cannot be left to small pockets of do-gooder healthcare professionals to handle. Providing a structured career path where healthcare professionals are able to enter and train in the field of palliative medicine directly without having to first enter other branches of medicine would help in redressing the manpower shortage.

Last but not least, is funding, which is not only required for a clinical service. It is also essential for research and education. In an ideal world, there would be a bottomless pot of money to fund all healthcare needs. However, the reality is that the field of dying, even that of children, is not high on the list of funding priorities especially when it has to compete for a limited amount of money with other areas in healthcare that focus on prevention and cure.

GRAVE LESSONS

Dying is a natural, inevitable outcome of being born. It takes courage and humility to acknowledge that we cannot cure all our patients despite all our treatment. The dying experience need not necessarily be negative and bitter. It has the potential to bring about tremendous healing as well as growth professionally and personally but only if we choose to see it as such.

The dying have a lot to teach us. As a doctor, these adults and children have taught me the art and science of medicine. As a person, they have taught me how to give unconditional love and care to others in need. It has been my privilege and pleasure to be able to care for them.

This article is dedicated to the memory of all children who have died, their families, the NUH paediatric oncology (PICC) unit, the KKWCH paediatric anaesthesia unit and the Assisi Homecare team. Thank you for allowing me to walk with you and inspiring me. ■