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More can be done for dying children: Study

Few families given option of letting the child die at home

By POON CHIAN HUI

IT GOES against the natural order of life, but children do die in Singapore daily — some painfully, and most of them in hospital.

A recently published study says that for the 68 children under the age of 19 who died of illness between 2008 and 2009 in Singapore, the option of having the child die at home was hardly offered to their distraught families.

Studies done elsewhere have noted that the families of as many as eight in 10 dying children would choose to take the child home if the choice was presented.

The fact that this option is hardly exercised in Singapore is all the more surprising when caring for a dying child at home can be arranged, even if medical equipment like respirators needs to be set up.

The study also found that among the eight in 10 patients with cancer, only half were referred for palliative care, when all

of them, and their families, could have used such support.

The researchers from KK Women's & Children's Hospital (KKH) and HCA Hospice Care, whose study made it to the Singapore Medical Journal last month, thus concluded that more can be done to improve the care given to critically ill children.

The study, done in a period of nearly 40,000 admissions to KKH, excluded 24 other children who died of other causes, such as in accidents.

Apart from the eight in 10 who died of cancer, the others died from infections or heart and congenital problems.

The researchers expressed the hope that doctors and parents would seek palli-

ative care for sick children earlier, instead of only when they are about to die.

Lead researcher Chong Poh Heng said: "Many children die 'invisibly' because people don't want to talk about it."

The truth is that about 300 children die here every year.

But when the subject of palliative care comes up, it is more likely than not to be in reference to care given to the ailing elderly.

The study did, however, unearth one bright spot — that "advance care planning" is satisfactory.

By this, the researchers meant that in seven out of the 10 cases in the study, the families were told that the child's illness was critical, and were consulted on how they wanted the child's care to be managed.

This included following through on a "do not resuscitate" order to spare the dying child the trauma of being revived.

Dr Chong, explaining the rationale for the study on critically ill children, said: "By knowing what their dying experience was like, we can better define what specific needs these children and their families have."

As deputy medical director of HCA Hospice Care and a member of KKH's paediatric palliative service, Dr Chong holds the issue close to his heart.

He said that he has come across only one or two families every year who

choose to bring their child home to die.

The palliative care service can arrange for the simplest to the most complex medical support for families who want this option.

Yet, two-thirds of the 68 children in the study died in intensive care units in hospitals.

Health-care staff may find it difficult to raise the subject, for fear of being taken as having given up on the child's chances of recovery.

Parents themselves may hold off facing the issue, for fear that they may be unable to cope on their own at home, without doctors and nurses on call.

There is also the fear that moving the child home may compromise his or her chances of survival, or bring death sooner.

But a dying child who is moved home will receive visits

from doctors, nurses and social workers from the palliative-care service, said Dr Chong.

In fact, with the precious little time the child has left, this arrangement gives him or her quality time with the family.

Dr Chong added that children find more comfort in a familiar environment than in a "cold and clinical place".

"It is the only gift we can give to the family at this most difficult time."

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TABOO TOPIC

"Many children die 'invisibly' because people don't want to talk about it."

Lead researcher Chong Poh Heng. His team hopes that doctors and parents would seek palliative care for sick children earlier, instead of only when they are about to die

Star Pals give caregivers a break

A ROVING team is at the ready to support the families of critically ill children who have been discharged from hospital.

Called Star Pals, the team — comprising a doctor, four nurses, two social workers and a group of volunteers — provides a range of services.

This can include palliative care, and even "babysitting" the ailing child so the caregiver in the family can have a break to run errands or enjoy some personal time.

Started just this month, Star Pals is an expansion of the existing inpatient palliative care service run by KK Women's & Children's Hospital.

It is run in partnership with HCA Hospice Care, which already operates a similar programme for adults.

This way, the care given to a critically ill child starts during his hospital stay and extends to after the young patient is taken home.

The new service now runs on funding from the Tote Board, but hopes to be funded by the Government

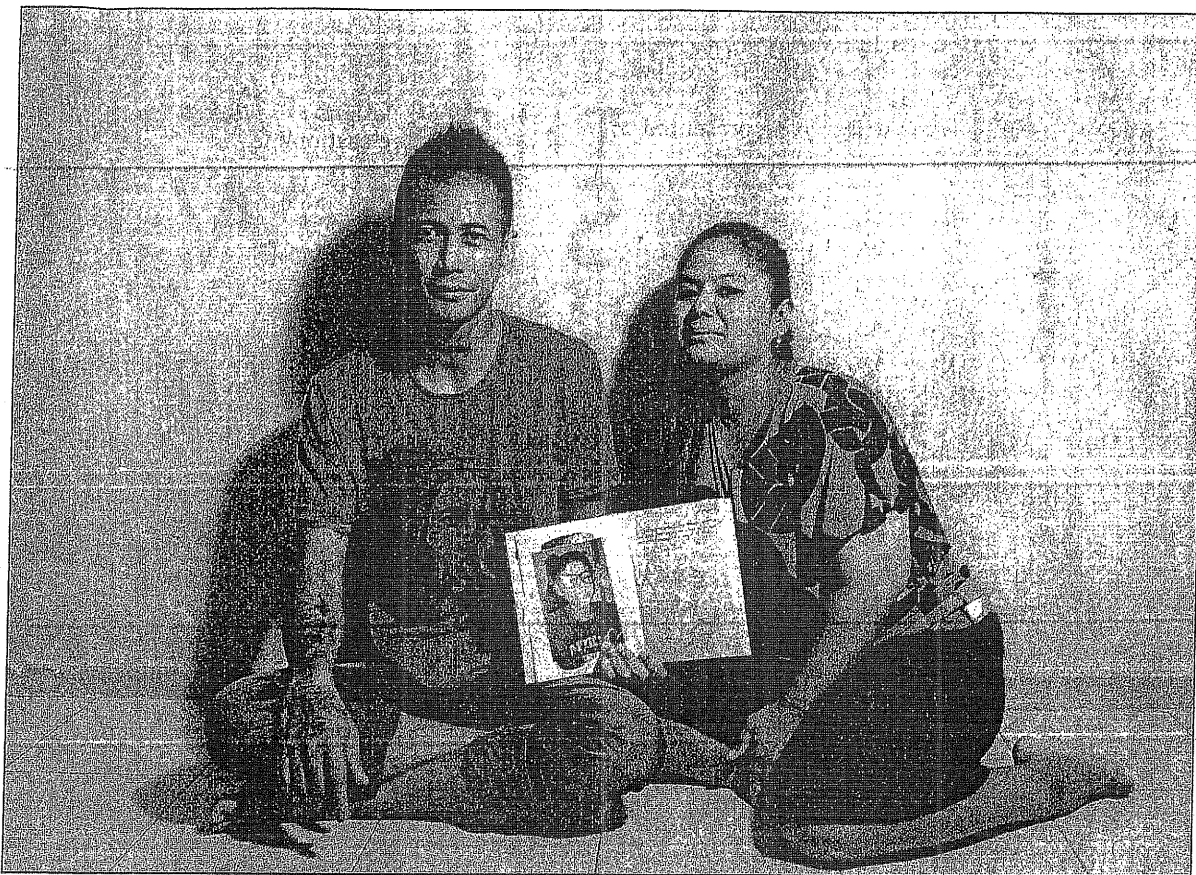
after three years, when the money runs out.

More than 20 families are now served by Star Pals.

Each pays \$30 to \$90 a month, depending on a means test they take; those with financial problems can ask for aid from other funds from HCA Hospice Care.

The service is open to everyone — young patients from other public hospitals as well as those from private hospitals may also sign up for it.

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Mr Juraimy and Madam Raba'ah, holding the diary that their daughter Amy Nabel'la Juraimy, 13, kept. Stricken with bone cancer, Amy chose to go home and managed to spend quality time with her family in her last days. ST PHOTO: JASON QUAH

Family together at home in girl's last days

TWO days into intensive care in National University Hospital, it was clear Amy Nabel'la Juraimy, 13, was not going to make it.

She was dying of bone cancer.

Her mother, Madam Raba'ah Abdul Ghani, 39, told her in tears that her doctors could not do anything more for her.

Amy, struggling to breathe, said to her mother: "But you always asked me to fight."

Her mother replied: "Mummy will always fight with you."

That was when Amy asked to go home. The choice, made last month, was the right one.

Her father Juraimy Difari, 39, said: "Amy was very happy when she came home."

In the last week of her life, Amy asked for – and got – her favourite foods and soft drinks, which the hospital would not have served.

More importantly, she spent quality time joking around and having meals with her parents and six siblings.

A nurse from HCA Hospice care made daily visits.

Madam Raba'ah said: "We

wanted us all to be together, under one roof."

She recalled how it pained her then to leave Amy in the hospital when the time came daily for her to go home to her other children.

"When I came back, I saw her struggling to breathe. It made me very regretful that I didn't stay with her," she said.

Mr Juraimy said he had wanted to take his daughter home when she was diagnosed with end-stage bone cancer last July, "but we didn't want Amy to think that we didn't love her".

"We wanted to show her we were fighting with her."

And fight, they did.

After the medical treatment failed, her parents spent money on health supplements and traditional remedies for a sliver of hope – not that there was much money to spare. Mr Juraimy, who earns about \$850 a month as a cleaner, worked seven days a week, and rode a bicycle to save on bus fare.

Thankfully, Amy's medical bills have been covered by the Children's Cancer Foundation.

Amy had no illusions about her chances. Three days after she returned home, she called her parents to her side to give them each a traditional greeting in which one kisses the hand of an elder as a mark of respect.

Kiss me on the cheek, she asked of her mother. She then placed her father's hand over her mother's and said: "Take care of Mummy."

She made her family members promise they would not cry when the time came.

The next morning, she told her father that she had seen men in white coming to carry her away. Amy was lucid, free of tubes that would have tethered her to life-support machines, and free of sedation.

Her mother whispered: "If you love me, go. Don't fight it."

Holding her parents' hands, Amy took three slow breaths and then a final one at 4am on a morning in March.

Her family was quiet. No one sobbed. It was just the goodbye she had wanted.

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