

Parents' perspectives on the important aspects of care in children dying from life limiting conditions: A qualitative study

Kuan Geok Lan, MSc Pall Med (Cardiff)*, Low Wah Yun, PhD**

*Department of Paediatrics, Malacca Hospital, Malacca, Malaysia. **Medical Education & Research Development Unit, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia

ABSTRACT

Introduction: The importance of Paediatric Palliative Care (PPC) is increasingly recognised worldwide, with the World Health Organisation (WHO) and the American Academy of Pediatrics (AAP) endorsing the development and wide availability of PPC. When these children are in the terminal phase of their illness, PPC should be tailored to the different needs and desires of the child and the family, with the goal of providing the best possible quality of life (QOL) for the days that remain.

Method: Malaysia has yet to develop a national PPC policy. In anticipation of this, as part of a needs based qualitative study, parents' views were solicited, as to the unmet needs of their children during the terminal phases of their illness. A purposive sampling was conducted amongst fifteen parents of nine deceased children (ages 2-14 years, eight cancer, one Prader Willi Syndrome) who had received care in the Paediatric Department, Malacca General Hospital, a Malaysian government hospital. Two focus group discussions and three in-depth interviews were conducted, based on a semi-structured interview guideline. The interviews were audiotaped with permission and the tape recordings were transcribed verbatim. The data were managed and analysed by NVivo 9 software using a thematic analysis approach.

Results: The frequently emerging themes were the strengths and weaknesses pertaining to the healthcare system, processes within palliative care. These were symptom control, closed communication and lack of support and anticipatory guidance as death approached.

Conclusion: Dying Malaysian children and their families deserve to receive care that is more consistent with optimal palliative care.

KEY WORDS:

End of life, life limiting conditions, paediatric palliative care, qualitative research

INTRODUCTION

Paediatric palliative care (PPC) in Malaysia has been ranked as capacity building level only, yet to reach mainstream providers.¹ Care for most children in need of PPC is patchy,

inconsistent, mainly hospital based, and looked after by interested paediatricians in government hospitals without a formal PPC program.²

Data on incidence of children with life limiting conditions (LLC) in Malaysia is scanty. Lethal congenital malformations accounted for 25% of all deaths in children under-five-years, with 7-13% in metabolic, nervous and respiratory systems whilst oncology contributed to only 3.7% deaths. These deaths were more likely to occur in hospital than at home.³

Malacca Hospital is a government hospital with 10% (96) paediatric beds. PPC was first introduced into the department in 2007, with training and focus on symptom control; 40% of the deaths (2008/9) were found to be palliative in nature. When these children are in the terminal phase of their illness, PPC should be tailored to the different needs and desires of the child and the family, with the goal of providing the best possible quality of life (QOL). Were there unmet needs in these dying children? Was the support given for both hospital and non-hospital deaths sufficient?

This study aimed to gather parents' experiences in the end of life (EOL) care of their children, and gather their parents' views, needs and concerns of the level of support given to them.

MATERIALS AND METHODS

LLC deaths beyond the neonatal age up to 18 years, within 2008/9 were reviewed, in the Paediatric department, Malacca Hospital. Sudden deaths and non-LLC deaths were excluded.

These data were collected qualitatively, through focus group discussions (FGDs) and in-depth interviews (IDIs). Consent was obtained from the Ethics committee, Malaysian Ministry of Health. Participation information leaflet and consent forms in three languages were prepared to enrol interested parents. Data from the interviews were audiotaped, translated (if necessary) and transcribed verbatim. The data were managed and analysed by NVivo 9 software using thematic analysis and a constant comparison approach.

During the study period, 24 children with LLC were identified, however parents of eight children were non-contactable, three declined. Finally parents of the remaining 13 children were shortlisted for the interviews.

This article was accepted: 10 August 2015

*Corresponding Author: Kuan Geok Lan, Department of Paediatrics, Malacca Hospital, Jalan Haji Mufti Khalil, 75400, Malacca, Malaysia
Email: kgeoklan@yahoo.com*

Nine parents of five deceased children participated in the first FGD, conducted in English and Bahasa Malaysia. The second FGD involved four parents of three children, conducted in English and Mandarin. The ethnic diversity (Malay, Chinese, Indian) of Malaysia was taken into account. All the transcripts were translated into English. On the average each FGD took approximately 1.5 – 2 hours, whilst the IDI lasted about 45 mins - 1 hour. After interviewing 14 parents of nine children, it was felt that saturation had been reached.

RESULTS

The demographic data of the nine children is shown in Table I. There were nine mothers and five fathers, age range 33-54 years, median age 44 years. The majority completed secondary school education, one completed primary school and two at tertiary level. The mean income per month is RM3,000.

Views on Healthcare System:

Although there exists a misperception that patients who are admitted to any government hospital usually have negative consequences, there was a general satisfaction with the healthcare system, and on the strength of the therapeutic relationship.

"I don't understand why the public perceives that if you go to a government hospital, you are bound to die! The staff has been efficient and always encouraged and enquired after my well being. As the sole caregiver, there were many occasions when I felt like running away from it all....."

The salient themes that emerged were **communication** and processes within palliative care: **poor symptom control, choices of place of death, lack of a key worker, a terminal care plan and practicalities after a home death.**

Communication:

Five of the nine children were aged 10-14 years, yet in only one family was communication open, with the patient fearing he will be forgotten should his toys be given away. *"Mum, please forgive me for always taking it out on you." (voice breaks and cries), Mum, when I am gone, please do not give my toys away."*

Four families hid the diagnosis from the child; communication was closed with parents, and child in mutual pretence. Two sets of parents assumed that their child knew about the terminal nature of their illness whilst, a parent struggled with telling.

"I suggested that should I pass away before him, he will have to perform the final rites. He tearfully reprimanded me and wanted me to stop talking about death!"

"We believe he knows as he has asked me and my wife separately if he had cancer!" Although his parents evaded answering, they felt he knew because of his easy access to resources in the internet. "It is a circle of life; we have watched the documentary. He loves animals; he knows what the circle of life is."

"She knows! I had some issues I wanted to speak to her about. However when I observed that she confided in her older sister e.g., bequeathing her handphone to her mum, I felt she knew about the terminal nature of her illness. I can say that, as we have sent her for religious training about life cycle. So indirectly she knows. I am confident she understood (clears throat). She knew and she was prepared."

These parents felt that the breaking of bad news to the child, should be the parents' duty and the staff could offer to help parents talk to their child. Concern was expressed over timeliness, taking into cognizance the fragile mental status of the child as well as the skill of the healthcare professional to communicate honestly and compassionately, and be able to navigate the child's mood swings. Parents fear too, that incidents of careless and insensitive remarks can potentially cause the family lasting pain and complicate their grief.

Poor Symptom control:

The majority of patients in this study died from cancer. Dyspnoea, pain, lethargy and sleepiness were some of the symptoms described (Table I). Of six patients in pain, only one was well controlled, the remaining suffered needlessly despite morphine having been prescribed to all.

Choice of place of death: hospital

Two parents preferred their child to die in the hospital for relief from pain and suffering

"Not that we are clinging on hopelessly by bringing our child to die in the hospital, but we want our child to be comfortable, thus bringing him to hospital will ensure that should he be in pain, the pain can be relieved."

"He wanted to stay at home, saying 'I am dying, Grandma has come to bring me' but he was suffering, so we decided to bring him to seek treatment. We would have preferred to let him spend his last moments at home."

Of the nine patients, four died in the hospital and five at home. In the former group, two would have preferred to die at home, therefore the majority (77%) preferred home to be the place of death.

Choice of place of death: home

Of the five who died at home, two were in accordance with the child's wish,

"The doctor asked my son 'If you were to sleep for a very long time and will not wake up, where do you want to sleep: at home or hospital? My son said, 'at home, I want to stay at home."

"He also wished to be at home with his siblings. Even after he lost his vision, he was still playing with his younger brothers. His younger sister fed him."

Three were in accordance with the parents' wishes.

"Firstly we disliked the hospital, perhaps because he had spent too long a time in the regional and local hospitals. We just wanted it to be at home, because of the family; environment is also different. Tsk!"

Table I: Characteristics of diagnosis, ages, place of death and duration since death

Patients	Age years	Diagnosis	Place of Death	Symptoms	Duration since death
P1	10	AML	Home	Pain	1year 4 months
P2	14	Ewing's sarcoma	Hospital	Pain, dyspnoea.	2 years
P3	3.4	Prader Willi Syndrome	Hospital	Dyspnoea	1 year 3 months
P4	2.3	13q deletion retinoblastoma	Home	apnoea	1 year
P5	10	T Cell ALL	Home	Breathless, lethargy, pain	1 year 3 months
P6	10	AML	Hospital	Ventilated	23months
P7	5	B ALL	Home	Pain	1year 3 months
P8	14	Ewing's Sarcoma	Home	Pain	1year 5 months
P9	3	Pelvic rhabdomyosarcoma	Hospital	Pain	1year 8months

Lack of a keyworker

It appeared that the impact of the lack of support was acutely felt by parents who opted for home care especially during crisis. Some frustrations expressed:

"One night when he was in pain, we called the ward but the line was passed from one doctor to another. It was all very exasperating, there was no one to give us advice."

"I think during the weekends, it will be beneficial if there is someone we could call and say he has this symptom, what should we do? "

"Towards the end he suffered a lot...It would have been good if during the terminal phase, a team from the hospital could visit us and ease his discomfort and suffering, at least he could have been satisfied during his last moments, seeing he wanted to go to the hospital to have his pain addressed."

"Being non professionals we did not understand what was happening to him. It was purely guesswork! So far, thank God, he didn't suffer until the last like nine hours. He refused to take any morphine. So after another two hours he said, "bring it here, bring it here." That was the first and last dose of morphine for him. He passed away five hours later."

"We were absolutely clueless when he was breathing heavily at his last moments. A doctor would know what to do at that critical moment. When his grandmother passed away, her eyeball rolled up prior to death. For him, it was difficult as he had secondaries in both eyes. Initially I thought the noisy breathing was due to flu, but as time passed, I started to sense that something was wrong."

The lack of a key worker 24/7 left parents to navigate the healthcare system on their own, with no support and anticipatory guidance, especially during the night and weekends. A dedicated home care team could have addressed the symptom control in dying children as well as be able to diagnose the dying phase and death rattle.

Lack of a terminal care plan:

A parent did not anticipate the death of their son, when he passed away in the evening "unexpectedly". Thus, mum was totally unprepared and was in a state of shock to discover her two-year-old son was unresponsive. She single handedly drove and rushed her son to the A&E department of the hospital. *"I sent him to the hospital and the doctor kept on questioning for his name; his problem, his feeding? I know they need to ask the questions but at that time, I was really so distraught and shocked, I didn't know what to answer! (tears*

welling in her eyes) I just wanted to know the outcome of my son!" Had a terminal care plan been drawn up for the patient, the transition at the A&E could have been smoothed.

Practicalities following a home death

It is required by law for all home deaths to be notified to the local police station, before a death certificate and burial permit is issued.

A father had to make a defence with the visiting police officer who suspected child abuse because of the purpura. This was quite distressing for the family.

Added another mother:

"When my son passed away, the police officer who came to my house insisted on a post mortem despite me showing the hospital booklet verifying my child's condition."

DISCUSSION

The interviews provided valuable information regarding specific ways in which the palliative care services might be improved.

Generally children with malignant disease appear to have a precocious understanding of the concepts of death.^{4,5} Their experiences during treatment might include the deaths of other patients, and they can sense the extraordinary stress of their parents and doctors when death is imminent, as well as feel tremendous isolation if they are not given permission to talk openly about their illness and impending death.⁶

Whilst knowledge of the developmental understanding of death and timing is critical when it comes to communicating with children, it is also important to be receptive to when the child is initiating a conversation. "Teachable moments" may be fleeting, and healthcare workers need to be trained and tuned to these moments, so that it can be capitalized with an immediate response.⁷

Parents who wish but do not know how to break the news to their child are offered assistance by trained staff. The practice of collusion and mutual pretence seems to be commonly adopted by Malaysian families. Asian cultural practices and beliefs may influence the degree of open communication that takes place. An individual is not autonomous but lives in the context of a family and community.⁸ In the case of minors and elders, healthcare decisions are often made by the family. As parents are the final arbiters on decisions and assent⁹ a collaborative disclosure process taking into account

the family's wishes within the context of its culture will likely offer greater benefit overall, than would overriding and undermining the parents' role in promoting the long term autonomy and well being of their children.

The symptom burden of children dying from cancer in the last week of life has been described to be high.^{10,11} Pain as a symptom was suffered by 53-80%; with less than 30% successfully treated.¹² A majority of our patients were in need of regular pain medication, whether at home or in hospital. The median period being 6 weeks, mean duration 17 days.^{13,14}

Poor symptom control prevents parents and their families to navigate the psychosocial and spiritual domains;¹⁵ parents of children with unrelieved pain were still affected by it four to nine years after bereavement.¹⁶ In Malaysia, Pain as a 5th vital sign is a healthcare policy; the concept of not reserving analgesia for end of life is a moral and ethical imperative, obligating clinicians to provide appropriate analgesia at any point in the course of the child's illness.¹⁷ However the barriers to opioid use requires that Malaysian healthcare professionals, patients and families need to be educated to enhance their understanding and acceptance of pain treatment.¹⁸

None of our patients had a terminal care plan; hospital deaths has been shown to be the default situation, in such circumstances.¹⁹ Allowing children with life limiting conditions to die in a helpless state i.e., omission of a terminal care plan causes severe physical, emotional and spiritual pain to both family and staff.²⁰ To this end developing such a plan^{21,22} with the family and or patient is not an event but a process ideally built up over days, weeks and months.²³

Similar with other studies, half of our families chose hospitalization for end of life care with the hope that the child's pain can be better controlled.²⁴ The other half died at home which has been shown to be the commonest place of death for children dying of cancer in the UK¹³ as well as in five other nations, regardless of whether home care services are available.²⁵

These families need anticipatory guidance on a host of issues including education, preparation and practicalities especially after a home death. An official letter to the local police station from the doctors in the local hospital has overcome barriers in lodging a report on a home death. It is essential that a "key worker" or outreach nurse who interfaces between different care settings; the hospital, community and home, is available 24/7 to the family and be at hand.²⁶

The development of a terminal care program comprising a dedicated well trained personnel, providing prompt relief of symptoms, supervision, support, preparation of the parents for the death of the child, facilitating the child towards a "good death", will spare the parents and family members, the agony of inadequacy and lingering anguish and psychological consequences. How a child dies has been found to influence parents' abilities to continue their role functions as well as siblings' abilities to make and maintain friendships.^{27,28}

The lack of a local framework of a dedicated palliative care team, using a key worker concept, exposes these families to untold unmet needs, unnecessary pain and suffering, poor quality of life and deprives them of compassionate optimal palliative care.

Dying Malaysian children and their families deserve to receive care that is more consistent with optimal palliative care. To this end, there is a need for a systematic effort to train all healthcare professionals in communication and all aspects of paediatric palliative care, and the development of a multidisciplinary team with a key worker concept providing seamless, flexible and coordinated care.

This paper has several limitations that merit attention. It is based primarily on parents' perceptions, which were obtained 1-2 years after the death of their child. Parents' perceptions may not be an accurate reflection of the experience of their children, furthermore parents' perceptions and powers of recall may have changed over time. Selection bias in our purposive sample may have influenced the findings. It is plausible that those parents who were more satisfied with care were more likely to agree to this selective follow up interview.²⁹ Finally, the findings here reflect the pattern of care in only one of thirteen state hospitals in Malaysia; and may be less generalizable for other states.

ACKNOWLEDGEMENT

The author would like to express her gratitude to the Director General, Ministry of Health Malaysia for the allocation of a grant for the research. (NMRR-11-247-8331).

REFERENCES

- Knapp C, Woodworth L, Wright M, *et al.* Paediatric palliative care provision around the World: A systematic review. *Pediatr Blood Cancer* 2011; 57(3): 361-8.
- GL Kuan, Ednin Hamzah. Paediatric palliative care: Global perspectives; paediatric palliative care in Malaysia; chapter in book; 109-26 Springer, 2012.
- Wong SL. A study on the Under Five Mortality in Malaysia in the Year 2006. Ministry of Health Malaysia
- Spinetta JJ. Anxiety in the dying child. *Pediatrics* 1973; 52(6): 841-5.
- Bluebond-Langner M. Worlds of dying children and their well siblings. *Death Studies* 1989; 13(1): 1-16.
- Bluebond-Langner M. The private worlds of dying children. Princeton University Press 1978.
- Wolfe J, Friebergt S, Hilden J. Caring for children with advanced cancer, integrating palliative care. *Pediatr Clin North Am* 2002; 49 (5): 1043-62.
- Coward H, Sidhu T. Bioethics for clinicians: 19. Hinduism and Sikhism. *CMAJ* 2000; 163(9): 1167-70.
- Hilden JM, Watterson J, Chrastek J. Tell the children. *J Clin Oncol* 2003;21(9 Suppl): 37s-39s.
- Wolfe J, Grier HE, Klar N, *et al.* Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000; 342(5): 326-33.
- Drake R, Frost J, Collins JJ. The symptoms of dying children. *J Pain Symptom Manage* 2003; 26(1): 594-603.
- Hongi T, Watanabe C, Okada S, *et al.* Analysis of the circumstances at the end of life in children with cancer: symptoms, suffering and acceptance. *Paediatr Int* 2003; 45(1): 60-4.
- Goldman A, Beardsmore S, Hunt J. Palliative care for children with cancer - home, hospital or hospice? *Arch Dis Child* 1990; 65(6): 641-3.
- Sirkia K, Hovi L, Pouttu J, *et al.* Pain medication during terminal care of children with cancer. *J Pain Symptom Manage* 1998; 15(4): 220-6.
- Postovsky S, Ben Arush MW. Care of a child dying of cancer: The role of the palliative care team in Pediatric Oncology. *Pediatr Hematol Oncol* 2004; 21(1): 67-76.
- Kreicbergs U, Valdimarsdóttir U, Onelöv E, *et al.* Care related distress: a nationwide study of parents who lost their child to cancer. *J Clin Oncol* 2005; 23(36): 9162-71.

17. Contro N, Larson J, Scofield S, *et al.* Hospital staff and family perspectives regarding quality of paediatric palliative care. *Pediatrics* 2004; 114(5): 1248-52.
18. Grégoire MC, Frager G. Ensuring pain relief for children at the end of life. *Pain Res Manage* 2006; 11(3): 163-71.
19. Chapman JA, Goodall J. Dying children need help too. *Br Med J* 1979 1(6163): 593-4.
20. Masera G, Spinetta JJ, Jankovic M, *et al.* Guidelines for assistance to terminally ill children with cancer: a report of the SIOP Working Committee on psychosocial issues in pediatric oncology. *Med Pediatr Oncol* 1999; 32(1): 44-8.
21. Levi BH. Withdrawing nutrition and hydration from children: legal, ethical, and professional issues. *Clin Pediatr (Phila)* 2003; 42(2): 139-45.
22. Wolff A, Browne J, Whitehouse WP. Personal resuscitation plan and end of life planning for children with disability and life limiting/life threatening condition. *Arch Dis Child Educ Pract Ed* 2001; 96(2): 42-8.
23. Sleeman KE. End of life communication: let's talk about death. *J R Coll Physicians Edinb* 2013; 43(3): 197-9.
24. Papadatou D, Yfantopoulos J, Kosmidis HV. Death of a child at home or in hospital: experiences of Greek mothers. *Death Stud* 1996; 20(3): 215-35.
25. Davies B, Deveau E, deVeber B, *et al.* Experiences of mothers in five countries whose child died of cancer. *Cancer Nurs* 1998; 21(5): 301-11.
26. Jünger S, Vedder AE, Milde S, *et al.* Paediatric palliative home care by general paediatricians: a multimodal study on perceived barriers and incentives. *BMC Palliat Care* 2010; 9: 11.
27. Spinetta JJ, Jankovic M, Eden T, *et al.* Guidelines for assistance to siblings of children with cancer: report of the SIOP Working Committee on psychosocial issues in Pediatric Oncology. *Med Pediatr Oncol* 1999; 33(4): 395-8.
28. Hinds PS, Schum L, Baker JN, *et al.* Key factors affecting dying children and their families. *J Palliat Med* 2005; 8(Suppl1): s70-8.
29. Sandler I, Kennedy C, Shapiro E. Parental grief and palliative care require attention. *Arch Paediatr and Adolesc Med* 2004; 158(6): 590-1.