Paediatric palliative care in Malaysia: Survey of knowledge base and barriers to referral

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Background: Paediatric palliative care in Malaysia is underdeveloped, but there is recent increasing awareness and interest in this speciality. In September 2012, the Health Minister of Malaysia launched an initiative to support a nationwide provision of this service.

Aim: This study aims to explore the knowledge and practice of healthcare providers and their barriers to referral for palliative care prior to development of a nationwide service.

Design: Self-administered questionnaire survey.

Participants: Hospital-based paediatricians and paediatric nurses.

Results: There were 292 participants (69 paediatricians). The majority (92.7%) were females and the median age for the paediatricians and nurses was 37 years (range 27–60) and 31 years (range 21–58), respectively. General paediatrics was the predominant speciality of the respondents (61.3%) and 59.3% had more than 5 years paediatric experience. Of the 28.8% of the responders who thought they have basic palliative care knowledge, 40.5% believed morphine used in palliative care is addictive, 34.9% thought palliative care hastens death, and 44.3% were neutral or agreed that palliative care is associated with euthanasia. Over a quarter of all respondents (28.2%) professed to be confident in providing palliative care and 30.1% were confident in providing bereavement support. Of the 29% paediatricians confident in providing palliative care, less than half were confident of controlling pain or dyspnoea at end-of-life. The most common perceived barrier to referral by paediatricians (79.4%) was the lack of accessible palliative care services.

Conclusion: There is a lack of knowledge and understanding of palliative care among healthcare providers. Focused training and supportive policies are necessary to develop this service in Malaysia.

Keywords: Paediatric, Palliative care, Malaysia, Barriers, Training, Health education

Introduction

Paediatric palliative care promotes active total care for children with life-limiting illnesses and their families, with aims to relieve suffering and achieve the best quality of life possible in physical, psychosocial, and spiritual domains.¹ This specialized care is a developing subspecialty around the world.²⁻⁴ However, the extent of care provision in both developed and developing countries is still variable.⁵

In Malaysia, palliative care started with care for adults in the early 1990s, initially with home-based programmes by non-governmental organizations and subsequently inpatient units in government hospitals.⁶⁻⁷ The first palliative care inpatient unit in the country was opened in 1995 and by 2001 there were 11 inpatient units and 49 palliative care teams in government hospitals.⁶

Coordinated paediatric palliative care in Malaysia lags behind their adult counterparts. Individual paediatricians provide predominantly hospital-based end-of-life support to their patients. Some home-based services for adults would also deliver care for children and adolescents with a malignancy. There are 10.7 million children under 20 years of age in Malaysia (2010 census).⁸ It is estimated that the incidence of children with life-limiting illness is about 9570 per year.⁷

Recently, there is growing awareness and interest among paediatricians of palliative care needs of children and it is receiving recognition by policy makers. In September 2012, the Health Minister of Malaysia launched the ‘Paediatric Palliative Care Initiative’ to support nationwide provision of this service.⁹

In view of the recent service development, this study aims to explore the knowledge and practice of paediatricians and nurses and their perceived barriers to referral for palliative care prior to nationwide programmes.

Methods

This questionnaire survey was conducted between November 2012 and February 2013. The statements
in the questionnaire were modified from a literature review according to local needs and grouped into two categories: principles and practice of palliative care (22 statements) and perceived barriers to referral for palliative care (24 statements).10-14

A pilot survey was carried out on 16 paediatricians at a tertiary hospital. Following reliability analysis, statements with item-total correlations not within 0.3 and 0.9 were thought to be redundant or unclear and removed. The final self-administered questionnaire consists of 30 statements.

The questionnaires were anonymous and distributed at a local paediatric palliative care workshop in December 2012 and by paediatricians with an interest in palliative care at their hospitals. These paediatricians with interest in palliative care were identified from a national level service provision meeting. This approach to the survey was chosen to rapidly understand local needs prior to policies and due to limited resources.

All the responses to the statements were categorized on a Likert-like scale of 1 (strongly disagree) to 5 (strongly agree). The responses to the statements were recoded in three categories: ‘Disagree’ (responses 1 and 2), ‘Neutral’ (response 3), and ‘Agree’ (responses 4 and 5). Descriptive, chi-squared, and multivariate logistic regression analyses were conducted. A P value of <0.05 was taken to be statistically significant. All the statistical analyses were conducted using the IBM® SPSS® Statistical Software Version 21.0.

Results

There were a total of 292 participants (69 paediatricians and 223 nurses). The median age for the paediatricians and the nurses was 37 years (range 27–60) and 31 years (range 21–58), respectively. The majority (92.7%) of the respondents were female and 61.3% of the respondents practiced in general paediatrics. About 60% of the group had more than 5 years paediatric experience with a median of 11 years for doctors and 6 years for nurses (Table 1).

Significantly more paediatricians (40.5%) than nurses (25.1%) agreed to have basic knowledge in palliative care (P = 0.02). Multivariate logistic regression did not show any statistical significant association between profession (P = 0.54), age (P = 0.15), and years of paediatric experience (P = 0.13) with having basic palliative care knowledge.

Of all the respondents who agreed to have basic palliative care knowledge (28.8%), 40.5% thought the use of morphine in palliative care is addictive, 34.9% thought palliative care hastens death, 53.1% agreed that laxatives should be started with the use of opioids, and 44.3% were neutral or agreed that palliative care is associated with euthanasia (Table 2).

Over a quarter of all the respondents (28.2%) professed to be confident in providing palliative care. Multivariate logistic regression did not show any statistical significant association between profession (P = 0.30), age (P = 0.14), or years of experience (P = 0.27) with confidence in providing palliative care. Of all the respondents, 44.7% agreed to be ‘confident to recognize stress in patients or their families’, 45.5% agreed to be ‘able to recognize signs of impending death’, 32.9% were ‘confident in preparing patients and families for the eventuality of death’, and 30.1% were ‘confident in providing bereavement support’.

Table 1 Demographics of the survey respondents

<table>
<thead>
<tr>
<th>Gender (n = 273)</th>
<th>Total (%)</th>
<th>Paediatricians (%)</th>
<th>Nurses (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>253 (92.7)</td>
<td>45 (71.4)</td>
<td>208 (99.0)</td>
</tr>
<tr>
<td>Male</td>
<td>20 (7.3)</td>
<td>18 (28.6)</td>
<td>2 (1.0)</td>
</tr>
<tr>
<td>Age, years (n = 284)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 30</td>
<td>99 (34.9)</td>
<td>3 (4.7)</td>
<td>96 (43.6)</td>
</tr>
<tr>
<td>31–40</td>
<td>129 (45.4)</td>
<td>42 (65.6)</td>
<td>87 (39.5)</td>
</tr>
<tr>
<td>&gt; 40</td>
<td>56 (19.7)</td>
<td>19 (29.7)</td>
<td>37 (16.8)</td>
</tr>
<tr>
<td>Paediatric experience, years (n = 273)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 5</td>
<td>111 (40.7)</td>
<td>6 (9.4)</td>
<td>105 (50.2)</td>
</tr>
<tr>
<td>5–10</td>
<td>83 (30.4)</td>
<td>27 (42.2)</td>
<td>56 (26.8)</td>
</tr>
<tr>
<td>&gt; 10</td>
<td>79 (28.9)</td>
<td>31 (48.4)</td>
<td>48 (23.0)</td>
</tr>
<tr>
<td>Speciality (n = 271)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>166 (61.3)</td>
<td>35 (58.3)</td>
<td>131 (62.1)</td>
</tr>
<tr>
<td>Paediatrics</td>
<td>21 (7.7)</td>
<td>0</td>
<td>21 (10.0)</td>
</tr>
<tr>
<td>NICU</td>
<td>48 (17.7)</td>
<td>7 (11.7)</td>
<td>41 (19.4)</td>
</tr>
<tr>
<td>Oncology</td>
<td>23 (8.5)</td>
<td>6 (10.0)</td>
<td>17 (8.1)</td>
</tr>
<tr>
<td>Others*</td>
<td>13 (4.8)</td>
<td>12 (20.0)</td>
<td>1 (0.5)</td>
</tr>
</tbody>
</table>

(n = 292, paediatricians 69, nurses 223).

*Neurology, genetics, gastroenterology, respiratory, cardiology, and dermatology.

Table 2 Respondents who agreed to Have basic knowledge in palliative care

<table>
<thead>
<tr>
<th>Statements</th>
<th>Paediatricians, n/N (%)</th>
<th>Nurses, n/N (%)</th>
<th>p  value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphine in palliative care is addictive</td>
<td>0 (27/28 [96.4])</td>
<td>1 (28/36 [80.0])</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Palliative care hastens death</td>
<td>1 (28/28 [92.9])</td>
<td>1 (28/36 [80.0])</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Palliative care is associated with euthanasia</td>
<td>0 (26/27 [96.3])</td>
<td>1 (28/36 [80.0])</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Laxatives should be started with the use of opioids</td>
<td>17 (27/14 [14.3])</td>
<td>4 (28/36 [80.0])</td>
<td>0.13</td>
</tr>
</tbody>
</table>

(n = 84, paediatricians = 28, nurses = 56).
Of the paediatricians who agreed to being confident in providing palliative care (n = 20), 45% were confident of controlling pain and dyspnoea at end-of-life, respectively.

From all the respondents, the common perceived barriers for referral of patients for palliative care stemmed from the family’s understanding of illness and issues within the family (Fig. 1). Among the paediatricians, the lack of accessible paediatric palliative care services was the predominant perceived barrier to referral (Fig. 1). More than half of the paediatricians thought that ‘uncertain prognosis’ (50%) and ‘unsure when to refer’ (51.5%) were barriers. More paediatricians than nurses perceived that communication between the staff and the family and cultural differences were barriers to palliative care (Table 4).

### Table 3 Respondents who agreed to statements related to practical aspects of palliative care

<table>
<thead>
<tr>
<th>Statements</th>
<th>Paediatricians, n/N (%)</th>
<th>Nurses, n/N (%)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confident in recognizing stress in patients and families</td>
<td>43/69 (62.3)</td>
<td>87/222 (39.2)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Able to recognize signs of impending death</td>
<td>48/68 (70.6)</td>
<td>84/222 (37.8)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Confident in preparing patients and families for the eventuality of death</td>
<td>33/69 (47.8)</td>
<td>63/223 (28.3)</td>
<td>0.01</td>
</tr>
<tr>
<td>Confident in providing bereavement support</td>
<td>24/68 (35.3)</td>
<td>62/218 (28.4)</td>
<td>0.05</td>
</tr>
</tbody>
</table>

### Table 4 Comparison of what paediatricians and nurses identify as barriers to referral for palliative care

<table>
<thead>
<tr>
<th>Barriers to referral</th>
<th>Paediatricians, n/N (%)</th>
<th>Nurses, n/N (%)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor communication between staff and families</td>
<td>41/68 (60.3)</td>
<td>60/227 (27.1)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Cultural differences</td>
<td>35/67 (52.2)</td>
<td>78/220 (35.5)</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

Patient or families’ fear of morphine was not a common perceived barrier to referral for palliative care (31.4%). A minority of respondents perceived that staff wanting more life-sustaining treatment (27.9%), staff’s unrealistic expectations (21.6%), and conflict among staff about treatment goals (23.3%) were barriers to referral for palliative care (Fig. 2).

### Discussion

In Malaysia, patients with life-limiting illnesses are usually cared for by a general paediatrician at their hometown when discharged from the tertiary hospital by their primary team. There are 312 registered paediatricians in Malaysian government hospitals and 54% are general paediatricians. Of the 69 paediatricians in this study, 58% are general paediatricians reflecting the relative proportion in the country.

Less than half of the paediatricians and about a quarter of the nurses in this study felt that they have basic knowledge about palliative care. Lack of knowledge of physicians and nurses caring for palliative care patients have been reported in other developing countries. Education and training for all providers will be essential to ensure children and families get optimal care throughout their illness.
In this study, there were misconceptions about the concept of palliative care and the use of morphine; this was seen predominantly among nurses. Misconceptions among the nursing staff regarding the use of opioids have been observed in other studies as well.\textsuperscript{18,19} Nurses are important partners in the interdisciplinary palliative care team and have opportunities to forge close relationships with patients and parents. Hence, misconceptions by nurses may lead to similar misunderstanding by patients and families.

Age and years of experience of providers was not found to influence their perceived knowledge. Hence, training by role modelling may not be appropriate for now. Retraining of senior healthcare professionals will help ensure their support of the practices of junior providers with palliative care training.

Only 45\% of paediatricians who perceived themselves to be confident to provide palliative care, agreed to being confident of controlling pain and dyspnoea, which are two common symptoms seen at end-of-life.\textsuperscript{20} Less than half of the respondents in our study were confident in their ability to recognize signs of impending death or signs of patient or family’s distress, both of which are important skills of a provider. Michelson \textit{et al.}\textsuperscript{21} found similar findings, where at least 50\% of the paediatric fellows reported to have none or only minimal competence in managing pain and recognizing signs of impending death. Managing experiences at end-of-life are the expertise of palliative care providers and if not managed well can affect the subsequent grief experience of the parents.\textsuperscript{22}

Parental grief experience from the loss of a child can be prolonged and complicated; hence, bereavement support is an important aspect of palliative care.\textsuperscript{23,24} However, only 30.1\% of respondents were confident of providing bereavement support.

For patients and families to receive palliative care, healthcare providers would need to make the referrals. The overwhelming common perceived barrier to referral by paediatricians was the perceived lack of accessible services. Hence, communication between the service providers and the healthcare professionals needs to improve.

Both paediatricians and nurses perceived family’s understanding, expectations, and acceptance of the incurable illness, to be important barriers to referral. Similar findings were also reported by Davies \textit{et al.}\textsuperscript{14}, where family’s reluctance to acknowledge an incurable condition was reported by 51\% of the providers and family’s reluctance to accept palliative care was the top barrier as reported by Knapp \textit{et al.}\textsuperscript{13} This highlights the need for effective communication between the staff and the families, which itself was perceived by over 60\% of the paediatricians to be a barrier to referral.

Over half of the paediatricians were unsure when to refer and deemed uncertain prognosis to be a barrier to referral. The American Academy of Pediatrics had proposed an integrative model where palliative care supports patients and their families early irrespective of curability.\textsuperscript{25} Hence, healthcare providers need to be encouraged to refer early and not at end-of-life.

From this survey, a minority perceived healthcare professionals themselves to be barriers to referral to palliative care. This insightful perception will need to be addressed during training and providers may benefit from self-reflection of their own values and beliefs.

There was a statistical significant increase among paediatricians compared with nurses in their perception that communication and cultural differences were barriers (Table 4). Nurses who may have different communication agenda with families and have the
opportunity of more prolonged encounters with patients may not have seen communication as an important barrier. Specific perceived cultural differences were not explored in this survey, but this finding will be important for future studies especially in multicultural Malaysia.

Paediatric palliative care providers in Malaysia should continue to work with their adult counterparts, but will need to be mindful that there are differences in paediatric palliative care that are unique such as the developmental tasks of a child and the important consideration for the family’s needs.

As policy makers in Malaysia promote initiatives addressing access and service provision, it is important to have competent providers forming an interdisciplinary team to ensure patients and families receive quality palliative care. Training of students and current healthcare professionals of various disciplines needs simultaneous attention.

Integrated training approaches in both undergraduate and postgraduate curriculums could ensure multiple opportunities of exposures to the principles and practice of palliative care for students. Interactive learning and interpersonal skills training with role plays and case discussions as well as interactions with patients could more probably change the practice of providers than traditional classroom teaching. Observing and participating in an interdisciplinary team during training may be helpful in learning and would reflect actual circumstances in practice.

Re-education of experienced healthcare professionals via online self-education programmes may be an alternative to traditional didactic teaching. Online training has been shown to improve provider’s knowledge in the long term and their patient’s symptoms and quality of life. On site workshops and teaching-the-trainer sessions may be useful in view of the geographical distance in Malaysia. Whichever approach is taken, it will be important to subsequently assess the clinical effectiveness from the training provided.

Limitations

There are several limitations in this study. Not all hospitals in Malaysia were represented and hence the results may not reflect the perceptions of all the healthcare providers in Malaysia. This was a preliminary effort to obtain results rapidly to highlight to the policy makers the direction needed in promoting paediatric palliative care. It was thought that paediatricians with an interest would be motivated to distribute the questionnaires. All the responders participated voluntarily and may have formed a biased group.

The language of the questionnaire may have compromised the accuracy of the results for nurses who may be less fluent in English. Responders from subspecialties such as neurology, genetics, oncology, and intensive care were insufficient to extrapolate the perceptions of the healthcare providers in these areas.

Conclusion

As paediatric palliative care services develop in Malaysia, this study demonstrates the urgent need for education and training. Misconceptions and lack of practical expertise of healthcare providers will compromise the care children with life-limiting illness and their families receive.

Apprenticeship in training will not be appropriate for now as paediatric experience did not correlate with the perceived knowledge and practice in palliative care. Training of providers irrespective of experience will be required.

Effective communication with patients and their family is vital to ensure optimal service. Factors influencing provider’s communication skills will need to be explored.

To the best of the author’s knowledge, this is the first published study to explore perceptions of Malaysian providers on paediatric palliative care. From these results, further needs assessment and policies to support training will be necessary for the development of a nationwide palliative care service.

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