

Clinical Ethics Knowledge and Attitudes Among Malaysian Paediatricians

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Introduction:

Most medical practice guidelines expect all medical professionals to have knowledge of medical ethics.^{1,2,3,4} In Malaysia, most medical students do not currently get courses in ethics. Educators have suggested that courses in law and ethics ought to be introduced into the undergraduate medical curriculum to ensure medical practitioners are equipped to provide ethically appropriate care. This is especially complex in Malaysia, because ethics is embedded in culture and Malaysia is a complexly multicultural nation.⁵ Malaysia is also a developing country of diverse religious beliefs with many ethnic groups and wide income disparities.⁶ Thus, it is unclear what the content of a medical ethics curriculum ought to be.

Children who have a serious illness are a vulnerable group with no legal voice. Many doctors do not recognize that adolescents may have decisional capacity and may be capable of making autonomous decisions about their medical care. Paediatricians with training in bioethics may be better equipped to achieve what is best and least harmful for their patients and families. However ethical dilemmas in clinical practice are rarely recognised or discussed.

There are no known studies on the knowledge and attitudes of Malaysian paediatricians towards clinical ethics.^{7,8} In spite of the lack of data, but recognising the importance for medical ethics education, the National Paediatric Postgraduate Training Programme in Malaysia has just included paediatric clinical ethics in the new curriculum for the training of future paediatricians. (June 2019, personal communication with Dr. Farah Khalid who is a committee member of the team).

To inform this effort to upgrade bioethics education, we explored paediatricians' beliefs about four areas of clinical ethics; truth-telling, patient confidentiality, care in constrained resource situations and issues around end-of-life care.

Method:

This is a cross-sectional study using an online survey (Google Form). Institutional ethics approval was received on 7th January 2019 (MREC ID NO: 2018119-6869). Malaysian Paediatric Association email-blasted the survey to all paediatricians listed as members in their unverified email list. Heads of paediatric departments of seven referral hospitals were also sent email invitations with the online link to the survey. There was no inducements offered to participate. The survey was voluntary and anonymous unless respondents wanted to receive results of the survey. The online survey remained open for 2 months.

The survey was designed following a literature review and discussion with expert paediatric clinicians. The survey collected demographic characteristics and information on respondents' available guidance when faced with clinical ethical dilemmas. Participants were asked to rate their agreement to statements following four clinical scenarios based on a 5-point Likert scale. (Table I) There were a total of 27 statements.

Responses were analysed using SPSS version 25. Descriptive analysis were used and for Likert scale responses, median was used to measure central tendencies of responses to similar questions.⁹ Spearman correlation and Kruskal-Wallis and Mann Whitney non-parametric test were used in analysis. A $P < 0.05$ was considered statistically significant.

Results:

There were 68 respondents with median age of 40 years (range 32-63 years) and median years of paediatric experience of 13 years (range 5-36 years). About half (52.9%) were parents themselves and 69.1% were females. Majority (92.6%) were paediatricians working in hospitals and 66.2% of all respondents were general paediatricians.

A minority (19.1%) had formal medical ethics training and majority of them (76.9%) had more than 10 years of paediatric experience. When faced with a clinical ethical dilemma, 64.7% of respondents perceived to have guidance or avenues for case discussion. Of the 25 respondents who elaborated on their source of guidance, the most common (72.0%) was discussion and advice from their consultants, senior colleagues and head of department.

In Scenario 1, most (98.5%) respondents believed that it was appropriate and ethically justifiable to tell children the truth about their diagnosis and prognosis. Some changed their mind, however, if the parents forbade truth telling. Then, only 66.2% would tell the child the truth. Male paediatricians were more likely to be truthful to their patient about non-responsiveness to treatment even when parents forbade it. $P=.005$. There was no significant correlation with being parents in their decision to be truthful when their patient's parents forbade it.

Paediatricians' age was associated with paternalistic attitudes. Older paediatricians were more likely than younger ones to respect parental authority in withholding the truth from their child. This was not, however, statistically significant. $P=.253$ (Table II).

When parents preferred not to be truthful with their child, the number of respondents who would still be truthful when asked differed, at 'diagnosis' and 'when treatment fails' with a response of 69.1% and 95.6% respectively. Most respondents (64.7%) did not approve of the use of placebo pain medication. The more experienced paediatricians were statistically more likely to not approve the use of placebo. $P=.014$.

In Scenario 2, fewer respondents disagreed that medical information could be shared with patient's grandparents (50.0%) than with parents' close friends (92.7%). The median response to the five statements related to patient confidentiality showed 85.3% of respondents respected it. The older the paediatricians, the more likely they were willing to share anonymised patient's stories with their friends. $P=.014$ There were clinical differences in responses with whom patients information could be shared with. (Table III) Majority (91.2%) of respondents would not be social media friends with their patient's parents.

Scenario 3 revealed that half of the respondents will not discharge the patient who could benefit from being in hospital when parents who are foreigners and cannot afford to stay. When the hospital bill continues to escalate, 35.3% felt that they had to discharge the patient. Half of the respondents would want to crowd fund for required medical equipment to facilitate discharge and more than a third (35.3%) of respondents were neutral.

In the last scenario, 47.1% concur that parents can demand to continue non-beneficial life-sustaining treatments in a child with incurable disease. Respondents were also divided in other ethical issues at the end of life. (Table IV). However majority (85.3%) were comfortable with the double effect of interventions at the end of life.

Discussion:

The knowledge and application of clinical ethics is important for all healthcare professionals. Many, however, have no formal training in this crucial aspect of clinical practice. This study offers information on current attitudes of Malaysian paediatricians and could help inform the design of medical school curricula in ethics.

This study shows that a large majority of paediatricians believed that it was ethically appropriate to be truthful with their child patients. Many, however, would not be totally honest and would defer to parental requests to withhold information. Paediatricians need to balance their obligation to provide appropriate information, child's autonomy with parental authority.¹⁰ Paediatricians often have divided loyalties between parental preferences and children's rights.¹¹ These results suggest a need for education about communication skills. Doctors need to explore parents' fears in order to help them become partners in telling the truth to their children.^{12,13}

Most paediatricians in this study sample respect the importance of patient confidentiality. It is common local practice that extended family members such as grandparents play as important role as decision makers and hence this may explain why medical information is released more readily. This may reflect cultural beliefs about the multiple roles of grandparents in the family.¹⁴ Confidentiality may be defined as being "within the family," rather than it being seen as focused on the individual patient. There are benefits to this approach and it deserves further study.

Paediatricians in this study seem conflicted with their clinical role and the availability of resources to carry out their duties. The decision to crowd fund for a patient who is a foreigner with financial challenges had the highest percentage (35.3%) of paediatricians unde-

cided or 'neutral' in their response. This reflects the current ethical and medico-social challenges to provide equitable care.

Paediatricians were divided about whether interventions are no longer beneficial or burdensome at the end of life. This is similar to attitudes in other parts of the world.^{15,16,17,18} Education in this area will be helpful for paediatricians caring for children and their families at the end-of-life. Advocating for the child, considering the benefit burden ratio of interventions and collaborating with parents should be our priority. Forgoing medically administered fluids and nutrition is ethically acceptable practice at the end of life but is recognisably controversial in children as feeding is deemed a fundamental element of care.¹⁸ Bereaved parents have however reported to be satisfied when the decision to forego artificial fluids and nutrition was made at the end-of-life with emphasis on their child's quality of life.¹⁹

This study has limitations. It is a small study and thus not representative of all paediatricians in Malaysia. It was not possible to verify the percentage of paediatricians practicing in Malaysia who were reached by the study method. There may be a self-selected bias of paediatricians who responded. This pilot study doesn't allow discussion and clarification of decisions made when faced with these scenarios. Experience and age of paediatricians seem to play a role in ethical decision making. Further qualitative research should explore these issues.

In conclusion, the results from this pilot study suggest topics where there is a high degree of knowledge and relative consensus; and topics where there is more disagreement among Malaysian paediatricians. These results could help educators prioritise topics for clinical ethics education for paediatric trainees. Follow-up qualitative studies to explore the thoughts and challenges behind paediatricians' decision making for these ethical issues may help reveal further educational opportunities.

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