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Religious and cultural challenges in paediatrics palliative care: A review of literature

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ABSTRACT

Introduction: Paediatric palliative care aims to improve the quality of life of both the patients and their families when facing life-threatening illnesses. However, regions with strong religious and cultural practices made caring for ill children even more challenging due to the various, and at times, contrasting expectations from the families and the healthcare providers.
Objective: This article aimed to discover the challenges of paediatric palliative care delivery in the context of culture and religion.
Methods: A systematic review was conducted through an online search of three databases for free open access articles and book chapters published between 2000 and 2018: Medline, Scopus and Google Scholar. Search key terms included: culture, custom, spiritual, ethnic, or religion [AND] end-of-life, palliative care, cancer, hospice, [AND] children or paediatrics.
Results: Thirty-two (32) articles met the eligibility criteria. Out of these, five distinct themes emerged on the basis of implications for paediatrics palliative care. These include the *(i)* role of religion and culture in decision-making, *(ii)* the involvement of clerics towards the end-of-life, *(iii)* specific communication with the children and their caregivers about imminent death, *(iv)* the acceptance of autopsy and organ donation, and *(v)* spiritual coping strategies.
Discussion: This review paper provided an insight into the impact of religion and topographical culture to the paediatrics end-of-life care. Cultural and religious traditions are dynamic and cannot be generalized to all families, hence a guided framework is recommended for clinicians working in diverse ethnic population in dealing with culturally sensitive, end-of-life care.

1. Introduction

In the recent decades, studies have documented substantial suffering among terminally ill children as a result of their progressive disease process or treatment-related complications [1]. Dealing with these children is particularly complicated as they are naturally expected to have more years to live as compared to the elderly, whose time is due. Hence, paediatric palliative care was introduced to offer comfort to this special group of patients dealing with terminal illnesses and also, to offer support for the grieving family members.

Additionally, the gaps in paediatrics palliative care and family management have been identified to include inadequate symptomatic relief among suffering children [2], communication barrier that exists between the caregivers and the healthcare team [2], and the stress and guilt experienced by the parents or the caregivers [3]. However, little emphasis was given with regards to the cultural and religious expectations from both the dying children and their families.

Cultural tradition and religious practices may vary even within

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the same community. Even for certain practices, there is a grey area between cultural or religious considerations. In Asian facilities, it is not uncommon to witness a visiting shaman in a tertiary care setting, reading chants and mantras alongside a dying patient. Unfortunately, the more advanced healthcare centres are often viewed as sterile with rigid policy by not allowing any room for cultural practices to interfere with conventional medical care. This may be particularly discouraging for terminally ill patients whose needs may surpass the basic medical attention [6]. In this case, the medical team may be viewed as an obstacle between the patients' and the families' spiritual needs. The physician may also be blamed for the patient's demise by preventing this non-conventional care that they desire for their dying loved ones.

In the context of a child's imminent death, the issue of organ donation need to be discussed with caution and a degree of astuteness. While the demand for organ transplant continuously exceeds the organ or tissue availability, matters concerning organ procurement and retrieval are deemed sensitive and are poorly discussed even among medical practitioners, making disclosure and communication even more difficult when encountering eligible donor. Terminally ill children are potential sources of organ procurement; however the issue of organ donation was often discussed too late hence, within such narrow time frame, the families are often in a dilemma when deciding consent for their children. They often opted to decline the idea in fear of disfigurement to the physical body and foreseeable guilt. This may even be complicated by existing cultural views and acceptance within the community.

There is a paucity of literatures addressing both the cultural and religious challenges simultaneously when dealing with terminally ill children. Hence, this paper aimed to provide a thorough review of specific challenges pertaining to religious and cultural aspects towards paediatrics end-of-life care, in formulating a comprehensive paediatric palliative model particularly in Asia, where the culture is diverse.

2. Methodology

This is a qualitative systematic review completed through an online search of three databases for free open access articles and book chapters published between the year 2000 and 2018: Medline, Scopus and Google Scholar. The search key terms include culture, custom, spiritual, ethnic, or religion [AND] end-of-life, palliative care, cancer, hospice [AND] children or paediatrics.

2.1. Inclusion and exclusion criteria

Studies include data on care for human subjects (of less than 18 years old), including heterogenous samples, studies reported in English language and data reporting palliative care models, intervention, and/or outcomes of palliative care in any setting, inclusive of primary, secondary or tertiary care, home, and non-governmental provisions. Studies were excluded if they were commentaries or editorials from individuals or unrecognized bodies, and grey literatures.

2.2. Article selection, review and extraction

Eligible documents were retrieved and exported to Mendeley (Version 1.19.1) software. Removal of duplicates was done by one review author (AA) and further review of the titles and abstracts was independently done by another author (KK). Two review authors (AA and KK) went through all the full text for the remaining articles. Disagreements with regards to the article eligibility were reconciled through discussion. Retained references were divided into themes and analysed using qualitative methodology.

The literature was read several times and critically appraised by one independent reviewer whose primary interest is in paediatrics health care (KK). The literatures were grouped into either religious, cultural or religion and cultural categories before further data extraction was done to assess for thematic content for each category. Information collected from data collection process include: *(i)* study identifier (authors and year of publication); *(ii)* study design (setting and dataset); *(iii)* participants (inclusion and exclusion criteria, study population size and socio-demography); *(iv)* results and conclusion.

2.3. Data analysis

Statistical pooling of data was not done due to the variations in the study design, outcome variable and study instrument used. Hence, the study results were summarized in a qualitative approach.

3. Results

The digital search resulted in 704 records that were subsequently screened by the titles and abstracts, of which 32 were considered relevant and were retained for full review. The flow of study selection was conducted according to the PRISMA guideline (Fig. 1).

Majority of the reviewed studies were published within the past six years. Majority ($n = 20$) of the reviewed studies originated from non-Asian countries, such as the United States ($n = 13$), Canada ($n = 2$), Italy ($n = 1$), Brazil ($n = 1$) and United Kingdom ($n = 1$). Few were from Asian countries, such as Malaysia ($n = 1$), Taiwan ($n = 1$), Singapore ($n = 1$) and Japan ($n = 1$). Methodological quality varied considerably across the retained studies. Cross-sectional research articles were the most frequently discovered reference (7/32) and a few discovered studies were review papers or technical report ($n = 8$). Among the papers with scientific design, majority ($n = 15$) papers used a dataset from multicentre studies while eight papers were the results of a single centre studies. Articles were considered relevant if the content include information on methodological or ethical challenges in paediatric end-of-life management or palliative care research with respect to topographic religion and cultural norms.

Table 1 provides the summary findings related to the thematic analyses of religious and cultural challenges in paediatrics palliative care. Five distinct themes emerged based on the implications of religion and culture on paediatric palliative care. These include: *(i)* the role of religion and culture in decision-making ($n = 13$); *(ii)* the involvement of clerics towards the end-of-life ($n = 6$); *(iii)* specific communication with the children and their caregivers about imminent death ($n = 14$); *(iv)* the acceptance of autopsy and organ donation ($n = 5$); and *(v)* spiritual coping strategies ($n = 18$). Most of the articles ($n = 16$) discussed at least two themes in a single paper related to paediatric end-of-life care with an emphasis on specific communication with the children and their caregivers about imminent death and spiritual coping strategies.

3.1. The role of religion and culture in decision-making

Our study found that traditional healers were the first choice opted by families coming from the deep-rooted cultural regions when their children experience health issues [16–18]. Native Americans, in particular were found to prefer information to be shared with the eldest community leader before a cumulative decision is made pertaining to the subsequent plan of care [17]. Furthermore, a review article of 25 papers by Banerjee et al. (2011) found that religious and cultural practices are a norm when dealing

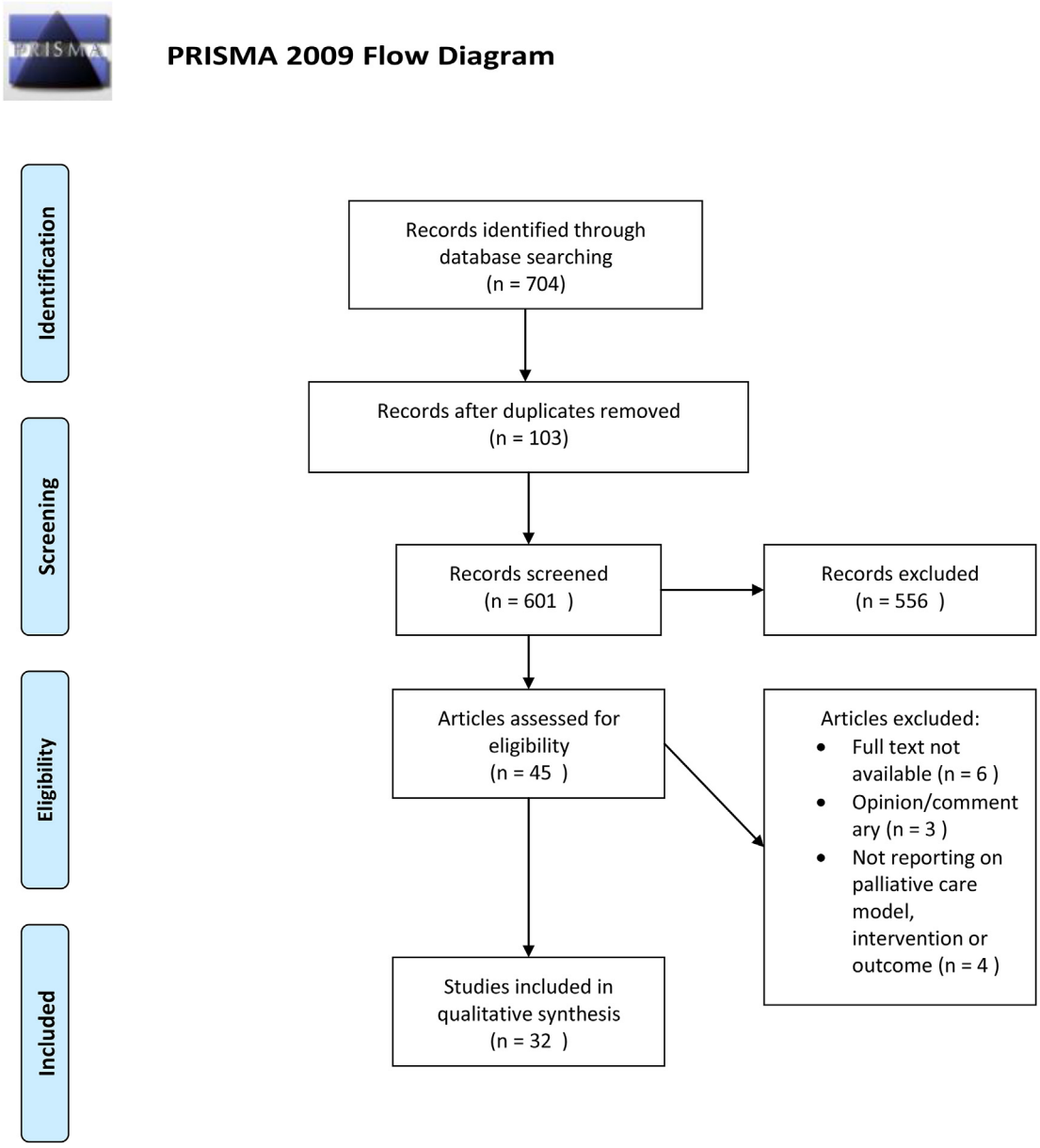

Fig. 1. PRISMA 2009 Flow Diagram.

with terminally ill children, such as drinking of 'purified' water read with Quranic verses by the Moslem patients, Shabad and Parth rituals among Sikh, or fasting in Hinduism [7], when dealing with health adversity of a family member.

3.2. The involvement of clerics towards the end-of-life

A multicentre study by Fitchett et al. (2011) found that 89% of the healthcare centres offering paediatric palliative care had staff chaplain as part of the unit [19] to address the spiritual suffering. The role of clerics were crucial as an integral part of PPC [19,20] and they assumed a professional role alongside with clinicians. Some centres offer the service of spiritual counsellors who provide spiritual support, perform religious practices by request of the family or patient, and provide emotional support to the families during the bereavement period [24].

3.3. Specific communication with the children and their caregivers about imminent death

Communication pertaining to imminent death in culturally strong and religious community is potentially difficult due to the difference in faith subscription between the families and the healthcare providers. A technical report published by the American Academy of Pediatrics (2000) supports that the provision of palliative care should respect the child's and family's wishes and preference to testing, monitoring and treatment [21] and this should include defining the child's view and inclination towards self-care [22].

3.4. The acceptance of autopsy and organ donation

Issues pertaining to autopsy and organ procurement mainly lie within the context of poor communication between the healthcare

Table 1
Findings: Thematic analyses of religious and cultural challenges in paediatrics palliative care.

No.	Theme	First author, year of publication	Design	Dataset	Findings
1	3	AAP, 2000	Technical report	NA	• Provision of palliative care includes sensitivity to and respect for child's and family's wishes; incorporates respect for terminally-ill child's preference – testing, monitoring, treatment • Majority did not have the benefit of PPS
2	1,5	Afungchwi, 2017	Cross-sectional ($N = 387$)	Multicentre, Cameroon	• 76.1% opted traditional healers as first choice when diagnosed with Burkitt lymphoma, due to family belief and disregard hospital treatment • >50% of Christians and Muslims opted for traditional healers
3	1,2,5	Banerjee, 2011	Qualitative ($N = 25$)	Multicentre, Canada	• Doctors taking care of child's cancer was equated to God's • Verses from Quran and blow on water for drinking • Sikh Shabad and Parth; Hindu fasting
4	5	Barton, 2018	Mixed methods	Multicentre, USA	• Interconnecting with God as the source of strength and social support • "Hope" is a helpful tool to navigate discussion by healthcare staff and adolescents/young adults • 2/3 of parents of seriously ill children were more comfortable discussing their religious/spiritual belief with chaplains than medical staff • Adolescents/young adults may decline chaplain support as they are questioning their own R/S
5	1,5	Brock, 2016	Retrospective cohort ($N = 445$)	Single centre, California	• Hispanic/Latino patients and Christian/Catholic patients were more likely to have DNR/POLST in place • No consensus on relationship between religions affiliation and end-of-life care in paediatrics • 15.5% received consultation of end-of-life care • Religiousness is an important predictor of aggressive end-of-life care
6	3,5	Chen, 2013	Cross-sectional ($N = 80$)	Multicentre, Taiwan	• 85% believe in transmigration of souls • To provide the best quality of life for dying patients and families, not to cure illness • To respect inescapable death without shortening life • 41% believed that parents were informed of palliative care option, 60% spent time with family • 30% had sense of failure when child dies
7	3	Chong, 2012	Retrospective cohort ($N = 68$)	Single centre, Singapore	• 89% had DNR orders when prognoses deemed poor; actively dying; 70% with decidedly dismal outcomes have advanced care planning; 52% with cancer were referred to palliative care for supportive management.
8	3,5	Chong, 2016	Retrospective cohort ($N = 137$)	Single centre, Malaysia	• 66 families discussed the preferred location of care at end-of-life • 78.9% died at home, as preferred • 93.3% families had bereavement follow-up visits • Late community care referrals (25.5% died within 2 weeks)
9	2	Fitchett, 2011	Qualitative ($N = 8$)	Multicentre, USA	• 89% had staff chaplain in PPC team (25/28) • 3 models of chaplaincy: regular participation in PPC round, unit chaplain in liaison with PPC, and student chaplain • Role of chaplain is to address spiritual suffering, as an integral part of PPC delivery
10	1,2,3,5	Hexem, 2011	Prospective cohort ($N = 73$)	Single centre, Philadelphia	• RSLF is important in tough times, participation in formal religious communities, or a sense of personal spirituality • Defining child's value and belief about afterlife.
11	1,5	Kato, 2004	Case report	Single centre, Tokyo	• Japanese views on life and death and disclosure of cancer contrast sharply with Western • Throughout the clinical course, spiritual and psychological care for the family should continue after the child's death • PPC is not common in Japan
12	5	King, 2017	Cross-sectional ($N = 172$)	Single centre, Seattle	• People with greater existential concerns report 5x religions/spiritual struggle, which is significantly associated with depression
13	4	Knapp, 2005	Technical report	NA	• No conducive environment in Emergency Department to cater for paediatric death – to address families' emotional/spiritual/culture needs and legal/procedural demand
14	1,3,5	McNeil, 2016	Review ($N = 8$ articles)	NA	• Religion positively correlated with more closely-knit families who grew closer with cancer diagnosis • To keep an open line communication and ensuring uninterrupted time to pray or read scriptures
15	3,4	Meert, 2015	Prospective cohort of secondary data ($N = 275$)	Multicentre, USA	• 63% had discussion on limitation or withdrawal of support during initial PICU stay • 37% had been approached for organ donation; 20% actually donated. 37% ($n = 79$) of autopsy requested from 213 non-medical cases, only 53 were performed • Overall, only 7% who died donated the organs. Overall consent rate is still low • There is reduced rate of paediatric autopsy despite its finding of important information in up to half of the cases • Further research and education is needed to optimize identification of eligible donors and consent process
16	5	Nicholas, 2017	Qualitative ($N = 31$)	Single centre, Canada	• Spirituality impact greater acceptance of parents' inability to protect child from harm related to illness, guidance/emotion decompression, support from community
17	5	Paisley, 2011	Cross-sectional ($N = 54$)	Single centre, Philadelphia	• 44% self-prayer and/or spiritual healing by others • 52% increased use of CAM after failed first-line therapy • 39% CAM-users felt the treatment was effective
18	5	Petersen, 2013	Review ($N = 51$ articles)	NA	• Spiritual care of a child with cancer – assessment of needs, assist in expression of feelings and concern, guide child in strengthening relationship, find meaning and purpose, find hope
19	2	Powell, 2015	Qualitative ($N = 18$)	Multicentre, USA	• Chaplains as a complementary team committed to patients, passionately
20	1,2,3,5	Proserpio, 2016	Cross-sectional ($N = 62$)	Multicentre, Italy and Spain	• Spiritual counsellor talks with patients, families, healthcare operators; perform religious activities on request, provide spiritual support for patient and family.
21	3,4	Serwint, 2002	Prospective cohort ($N = 75$)	Single centre, Baltimore	• Barriers to effective communication: weakness in medical education of healthcare providers and own interpersonal issues – may modify how a family copes, allay guilt of family

Table 1 (*continued*)

No.	Theme	First author, year of publication	Design	Dataset	Findings
					• Address issue of knowledge adequacy on organ procurement and donation and autopsy procedure through role-play and sharing of experience
22	1,3,5	Siegel, 2002	Cross-sectional ($N = 165$)	Single centre, Boston	• Intensity of S/R needs in adolescents increases with severity of illness • 35% of paediatricians believe they should initiate discussion on spirituality • 65% paediatricians felt faith play a role in healing
23	1	Singh, 2015	Systematic review ($N = 16$)	NA	• Dearth of data on cultural context of death and dying, hence need to response to the growing need of palliative
24	5	Sposito, 2015	Qualitative ($N = 10$)	Single centre, Brazil	• Understanding need of hope of cure and support in religion • Religion helped coping process in a way that cannot be explained in words
25	4	Stiers, 2015	Retrospective cohort ($N = 136$)	Single centre, Utah	• <10% terminally-ill neonatal referral to regional procurement organization for evaluation despite 44.1% met the eligibility criteria for DCDD • Non-referral or late referral is most frequent reason of donor ineligibility
26	1,2	Thienprayoon, 2013	Retrospective cohort ($N = 114$)	Single centre, Seattle	• Race/ethnicity significantly associated with hospice enrolment (Latino more likely to enrol than non-Latino) • Diagnosis significantly associated with hospice enrolment (Brain/solid tumor more likely to enrol than leukemia, lymphoma, SCT cases)
27	3	Thrane, 2017	Retrospective cohort ($N = 256$)	Single centre, Pennsylvania	• Role of palliative care is to reduce pain in children by reducing the suffering • Unfortunately, children were not referred to PPC until mere days before death
28	1,3	Tomlinson, 2007	Review ($N = 28$)	NA	• Issue of mistrust reported in different racial/ethnic perspectives between caregivers and parents. Caregivers should be trained in culturally and ethnically-oriented service provision • Child unaware dying or parents have yet to come to terms with a dying child
29	3,5	van der Geest, 2015	Cross-sectional ($N = 89$)	Single centre, Netherlands	• Child was parents' source of coping • 21% believed that faith and prayer is important during palliative phase; Dutch was found to be more secular • Honest communication of physicians do not impede sustaining hope
30	4	Weiss, 2016	Review ($N = 85$)	NA	• All pediatric DCDD donation can be practiced ethically • Autopsy procedures and policy, distinguishing SIDS from abuse, reassurance of no disfigurement need to be relayed to the parents – to have better understanding of spectrum of disease that might associate perinatal or childhood mortality including metabolic and genetic study.
31	1	Wiener, 2013	Review ($N = 37$ articles)	NA	• Native American preferred information shared with community leaders to help decision-making, to be first communicated to the eldest, male. • Japanese children rear practices with blurred boundaries between mother and child (Asian and Latino assumed mothers as primary caretaker, the one who made decision) • Parents prefer to oppose disclosure, conflicting healthcare and interfere preparation for dying among Chinese, Korean, Russian-American • Latino engage in rituals to remove evil spirits; Asians chose to augment conventional treatment with specific herbs
32	1,3,5	Zelcer, 2010	Qualitative ($N = 25$)	Single centre, London	• Parents find spiritual strength through maintaining hope and in child's resilience • Parents would prefer having the child died at home • Parents struggle to have conversations about death and dying

Note.
Abbreviation: CAM-Complementary alternative medicine, DCDD-Donation after circulatory determination of death, FT-Full text, NA-Not applicable, POLST – physician orders for life-sustaining treatment, PPC- Paediatric Palliative Care, RSLF-Religion, spirituality, lif e philosophy, S/R-Spirituality/religion, SCT – Stem cell transplant.
Theme: 1-Role of religion and culture in decision making, 2-The involvement of clerics towards end-of-life, 3-Specific communication with children and caregivers about imminent death, 4-The acceptance of autopsy and organ donation, 5-Spiritual coping strategy.
Abbreviation: CAM-Complementary alternative medicine, DCDD-Donation after circulatory determination of death, FT-Full text, NA-Not applicable, POLST – physician orders for life-sustaining treatment, PPC- Paediatric Palliative Care, RSLF-Religion, spirituality, lif e philosophy, S/R-Spirituality/religion, SCT – Stem cell transplant.

providers and the families [11], rather than due to the cultural and religious inhibition. Studies have found that late referrals were the commonest reason of organ ineligibility [12] and that education and awareness is needed to optimize identification of eligible donors and early consent process [23]. Despite the significant role of paediatric autopsy in offering better understanding of the disease with detailed analysis of the metabolic and genetic study [11], the rate of autopsy in paediatric setting is still low [23].

3.5. Spiritual coping strategies

Many parents experience stress and guilt when their young children suffer from terminal illness. A vast majority of faith believe in the transmigration of souls after physical death [5], that life simply does not end but continues in a different form. Developing a sense of personal spirituality and participation in formal religious communities were deemed helpful to help them through the difficult times [22]. Some families, on the other hand prefer to be at home towards the end-of-life [4], to give a sense of closeness and familiarity to the ill.

4. Discussion

This review paper provides an insight into the religious and cultural challenges when managing children end-of-life care. The thematic analysis from the study further highlights the fact that cultural traditions are dynamic and cannot be generalized to all families.

Conventional medicine is assumed as mechanistic and impersonal, whereby spiritual and religious needs are commonplace among Asian population, especially among adolescents [8]. The spiritual and psychological care for the family should also be continued after the child's death, in providing adequate social support [6,21] as bereavement process may even last way after the child's passing due to the remaining guilt and unspoken frustration.

Ambivalence is particularly ubiquitous among adolescents or young adults when dealing with terminal diseases. However, coping strategies in families with children who are too young to understand the concept of dying is more complicated. Spiritual coping was seen to have a better outcome of bereavement as it provides comforting belief and reassurance to the living [5,22,25].

The role of clergy has long been in the sublime. Studies found that having clerics involvement in the end-of-life care of a child does provide a positive milieu for the child and the family to communicate sensitive issues pertaining to the terminal disease and the trespassing of souls [19,24]. Clerics were assumed to be more socially-inclined and provide better empathy to the dying children and the family. Future role of a clergy as part of an integrated PPC approach is suggested to ensure holistic care to cater spiritual needs. Hence, mutual respect and appreciation between members of faith and medical team is encouraged through an interprofessional dialogue in the establishment of a community-model palliative care. Particularly in Asia where the cultural practices and religions are diverse, it is crucial to not place any stereotyping to any culture or religion practices.

Our study found that patients and their families were hesitant when discussing the religious and cultural aspects of dying with their physician [8]. The physician is often viewed as playing the rigid role of a healthcare professional, treating signs and symptoms and monitoring of laboratory markers. Caregivers ascribing to a different cultural practices and religion than that of their patients' may be placed in a difficult position when discussing the end-of-life planning. This is a common scenario experienced by healthcare providers particularly in Asian region where there is a widespread inter-cultural mingling. Therefore, the healthcare providers should be trained in culturally and ethnically-oriented service provision [9] to ensure effective healthcare delivery and establishing good patient rapport and compliance. The healthcare team should be aware of the commonly ascribed religion or local tradition of the native topography and has adequate information of their belief to assist in communication and in providing effective and genuine empathy without pretending affect. Additionally, a conducive environment is needed during discussion on end-of-life care to facilitate positive bereavement process [15].

Furthermore, issues concerning autopsy and organ procurement often accompany the end-of-life care. There was a low rate of paediatric autopsy being conducted despite legislative effort [10,11]. Autopsy may provide a better understanding of the spectrum of disease that might be associated with perinatal or childhood mortality, including metabolic and genetic study which may be beneficial in the long-term family planning [11]. Unfortunately, non-referral or late referral to organ procurement service is the most frequent reason of donor ineligibility [12] apart from the difficulty in getting consent from the next of kin. Siminoff et al. (2001) found that the strongest predictor of donation decision was the family's initial response to donation request by the healthcare providers [10]. Teenagers were found to be less willing to donate organs [13] and feel more discomfort as compared to adults, especially by the notion of becoming a part of another unknown individual through the donated organ. Therefore, healthcare professionals should be vigilant when communicating with the parents [14] as the families often find it hard to proceed with autopsy in view of fear of disfigurement to the body that they assume to be partly responsible for. Hence, promotion of a positive attitude towards autopsy may encourage the families to accept autopsy for legitimate reasons and discard their guilt and fear. Education to optimize the identification of eligible donors and consent process among families with dying children is deemed important to promote positive attitude towards donation, in both the public and professionals involved in the generation of organs.

5. Conclusion

Religious and cultural themes of individual patients and their respective caretakers should be addressed accordingly to ensure positive communication and individualized patient care. Children eligible for paediatric palliative care deserves to be given a timely PPC referral to support the need for appropriate symptomatic control, social support and emotional coping.

Cultural and religious traditions should never be stereotyped and each family ascribing to a certain practice should be respected and their cultural practices should be weighed against the conduct of conventional medicine. Often, cultural and religious practices act as a supplement to the instituted modes of conventional care, and not to intervene. Hence, a guided framework for the clinicians working in diverse ethnic provinces is recommended when dealing with culturally sensitive end-of-life care.

Declaration of competing interest

None.

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