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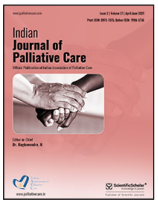

Commentary

The Science to Spirituality in Paediatric Palliative Care: A Commentary

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ABSTRACT

Spirituality in paediatric palliative care remains an enigma across both the Eastern and Western worlds. There is no absolute science to it, and it can be a barrier to effective palliative care to be delivered. This article aims to discuss the barriers to and recommendations for discussing this sensitive topic with children and their families to enhance the quality of palliative care rendered, with the aid of case studies to illustrate the underestimated importance of spirituality in paediatric palliative care.

Keywords: Spirituality, Paediatric, Palliative, Religion, Culture

INTRODUCTION

Dusk sets in the oncology ward as family members and relatives of a Gurkha child who is dying flock to her room. She is barely 3 years old and her megakaryoblastic leukaemia had relapsed after a failed transplant. Due to the COVID-19 situation, only a few relatives are allowed in. Normally, death is a ritual that encompasses many rites in Hindu tradition where extended family members and relatives will arrive from far and wide, to pay tribute and pray for the departing soul. The parents tell us, the ward team, that they have called the priest to come to do the final prayers. They kindly request that we write a memo to allow him in as visitor restrictions do not permit non-family members. The Vedic chants play on as the child becomes progressively dyspnoeic, as parents hold her hand, whereas relatives clasp their hands in prayer, hoping for her smooth transition into the afterlife. 'It is time,' her parents stoically tell me, as the saturations and heart rate drop to zero.

A few months later, the setting is the same; the oncology ward. This time an older Chinese girl is in her final hours. She had turned encephalopathic after her liver failed post-commencement of chemotherapy for a newly diagnosed Burkitt's lymphoma and she had a background of ulcerative colitis with autoimmune hepatitis and primary sclerosing cholangitis (PSC). She was well a few days prior before her sudden but anticipated deterioration. Her grandmother is by her bedside, quietly placing Buddhist beads in between her fingers, as she fluctuates between the stages of encephalopathy, turning progressively obtunded. Together with her mother, the ladies recite Buddhist chants, in faith that her passing on will be smooth and that she will be free of the troubles and suffering of this world as she heads a step closer to Nirvana. 'She has suffered enough,' her mother tells me, as I say my last goodbyes to the child I had journeyed with during her stay.

In the Orient where I come from, spirituality and cultural traditions play a massive role in paediatric palliative care as highlighted in the opening 2 anecdotes. Working in a tertiary paediatric institution in Singapore, we accord much respect to religion and faith in difficult times, especially in the neonatal and paediatric intensive care units (PICUs) and the oncology wards where death is often encountered, and spirituality provides an intangible support structure for families. While Western literature often avidly discusses debates on ethical or legal considerations in paediatric palliative care, there has been little focus on cultural care,[1] evidenced by a paucity of literature on this delicate subject matter. This critical appraisal will discuss the importance and impact of spirituality and religion in paediatric palliative care in both the local and international contexts, with recommendations on how to actively include it as a part of holistic care as it can pose a challenging and sensitive topic to the medical and nursing teams.

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There is no science to spirituality, which is defined as an aspect of humanity on how one seeks and expresses meaning and purpose, and how they experience their connectedness to the moment, to self, and the sacred.[2] It is indeed bewildering how large a role it plays in palliative care in Singapore, a crucible of many cultures and religions. Life and death are not only part of the life cycle but also rather there is more to both across various religious contexts. Furthermore, discussion on death is regarded as taboo in a society steeped in the traditions of the Far East. Palliative physicians, in general, must pay close attention when discussing this as a part of their palliative care framework for the individual patient as spirituality is no longer the sole duty of the chaplain.[2]

SPIRITUALITY IN PALLIATIVE CARE

[Figure 1] is a model I took from Cobb *et al*., which illustrates the relationship between how various factors contribute to and influence our spirituality and outcomes.[3] This model encompasses both the observable and unobservable or internal and external factors that mould all of us, be it parents, children, or healthcare workers. This in turn has an impact on how each of us perceives spirituality in the realm of palliative care from the one rendering it to the one receiving it. As our discussion unfolds, readers will be able to see how each component manifests and leads to some of the barriers encountered when rendering spiritual or cultural care. I felt that this was a very effective and concise model to illustrate my point.

SPIRITUALITY FOR THE FAMILY

Spirituality serves many functions for the family unit. Although it transcends our scientific rationale, it helps the family unit in many ways. Spirituality helps families to rationalise complex situations they may find themselves in – making life and death decisions with regard to advanced care planning or withdrawal of care in acute, sudden deterioration. It indirectly affirms their decisions and brings comfort and solace to the grieving or mourning using religion as a surrogate to even justify their decisions in certain circumstances. Spirituality also helps to maintain a form of hope, even in the darkest situations, although parents know that their wishes may not materialise.[2]

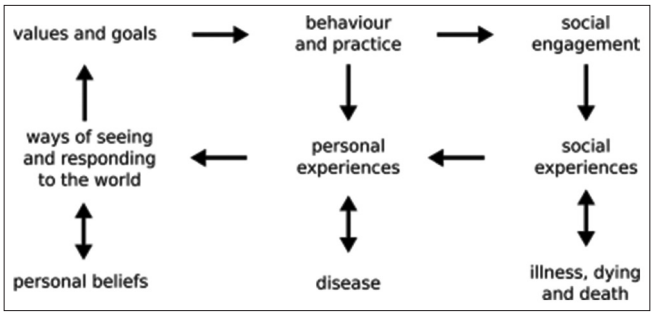

Figure 1: A synoptic model.[3]

Spirituality also helps to maintain a connectedness to the child after they have passed on. This was noted in a study where parents of children who died in intensive care, shared that they still remained connected to their children through various forms of imagery (associating butterflies with their child) or coincidental occurrences (flickering of lights or divine interventions when help arrives in an unexplained manner).[2] While parents do get angry with God during their journey, a study done showed that none continued to resent God even after their child died.[4] In my opinion, this is fair and healthy for the parents' emotional and psychological well-being as it helps them vent and go through the stages of grief before acceptance. Spiritual distress is a well-understood entity when a disturbance occurs to the belief system such as when a child falls ill,[5] and this further results in the need for support from the medical team.

Literature has also shown that spirituality has positive impacts on maternal mental health and parental burnout.[6]

SPIRITUALITY FOR THE CHILD

Children develop their own understanding of spirituality through different phases of growth, depending on factors such as exposure and how traditional their families are as well as how receptive they are to spirituality and religion. Amery *et al*.[7] proposed a modified table of spiritual development in children at different ages and the corresponding spiritual interventions.[8]

In the 2nd opening anecdote, the girl who had been newly diagnosed with Burkitt's lymphoma shared that she felt betrayed by God. She was raised with a Buddhist background and wore her amulet. However, when she first felt unwell, her aunt, who was Christian, had brought her to church to pray. She was optimistic that God was helping her till she found out about her oncological diagnosis, on a background of having battled ulcerative colitis with autoimmune hepatitis and PSC overlap. She told the social worker she felt that God had let her down. She lost faith. It is interesting how as a teenager, she interpreted her reality and grim prognosis as a form of spiritual 'let down', but this gives us an insight into the fact that spirituality not only affects the family but also the child.

This recurrent theme of punishment from God was also documented in a study by Dallas *et al*. who noticed a similar phenomenon amongst adolescents who were diagnosed with human immunodeficiency virus or acquired immunodeficiency syndrome.[9] Although there is a paucity of literature on understanding religion and views on God amongst children, these little anecdotes shed light on how they may try to make sense of their illness,[10] serving as a guide for the medical team to intervene to address their spiritual needs or misgivings.

For the younger children, there is ambivalence in terms of how they understand spirituality in the form of 'angels' as faith is magical and imaginative.[8] Furthermore, younger

children may complain of more physical pain and picking up the psychological pain to treat with spirituality may be trickier for the palliative team.[11] Hence, the healthcare team should cater to the various age-appropriate levels of spiritual needs in children of all ages for how one perceives death or 'the end' may not be the same as another (for example, a neonate versus a child versus an adolescent).

SPIRITUALITY FOR THE MEDICAL TEAM

The healthcare professional should acknowledge spirituality as a part of the human condition.[2] Families do appreciate a healthcare professional who understands how spirituality plays a role in their decisions for their children. One need not openly ask parents if their religious, but rather it has to be done appropriately. This will enable the medical team to better support the parents.[2]

Healthcare workers need to understand that parents are reliant on spirituality not as a complete dismal of reality but rather in need of an external pillar of support.[4] Hence, we should capitalise on this and empower parents to make decisions and help them to arrive at their own conclusions.

Communication is important in conveying our confidence in the role spirituality plays surrounding a child's death. How we speak to the child even after the child passes demedicalises the process of death.[12] These are little gestures we do, without even realising it, on a quotidian basis that families really appreciate.

Spirituality can also be used to ameliorate the physical state of pain. If it brings comfort to a child or if it relieves the stress of the family around the child, I do feel it can indirectly relieve pain as a form of mental distraction. Spirituality can also allow the medical team to intervene with necessary treatments or optimisation of treatment as certain if not most, religions prefer the child to pass comfortably.[13] An example was the Gurkha child in the first anecdote, whose parents clearly stated their wish for her to pass without anguish so that she could comfortably go to the afterlife.

When it comes to hoping for miracles, hoping is a part of an effective coping strategy.[11] Healthcare workers should try to acknowledge this and help guide parents along this difficult journey.

BARRIERS

A potential barrier that may disrupt spirituality for the family and physician's understanding is when there is a conflict between faith and medicine. For example, if parents hope for a miracle, but the medical reality differs, it may be difficult for physicians to bridge the glaring disparity between religious hope and medical limitations.[4] This is a very well-established grey area, especially in intensive care where we do encounter children who drown and who arrive with hypoxic ischaemic encephalopathy secondary to prolonged downtime. Parents beg us to do all we can but in reality, we know the prognosis is poor.

I remember doing my night rounds in the PICU when a girl was admitted for accidental drowning and her mother, who was a staunch Roman Catholic, was praying over her, refusing to listen to the withdrawal of care. Furthermore, the PICU consultant had also opened the discussion of organ donation, and this made them irate. I remember the father saying, 'Why should I save others when others could not save my child in time.' I do wonder if giving the parents time to use their spirituality to understand the reality may help them navigate through such challenging conversations.

Cultural bias may occur when healthcare workers are of a certain faith, making it easier to understand the belief systems of certain families better than others.[12] Up to 40% of healthcare workers found cultural differences as a significant barrier to adequate palliative care.[13]

Healthcare workers need to be open to concepts such as miracles. While some feel that it diminishes their ability to prognosticate, making them more cautious,[4] it is an allowance that we as healthcare professionals must give ourselves. It may generate a contradiction between how the team may have anticipated the course of the child and the eventual outcome, but we all hope for the best and should communicate our intentions clearly to parents. Denying any possibility of one, on the basis of absolute clinical objectivity, may lead to a breakdown in the therapeutic alliance.[14]

Establishing a curriculum to teach healthcare workers about spirituality is not possible as everyone has different levels of comfort with their own spirituality. Dealing with this on a constant basis may result in compassion fatigue, burnout, and increasing self-vulnerability[12] as not all of us may be readily spiritually available.

Time constraint is also a real barrier as nursing a child with palliative needs may take precedence over dealing with the intangible.[5]

Recommendations

The role of the healthcare worker in being the bridge between the chaplain and the family cannot be understated and we need to increase our awareness not only for the families but also for the children.[12] The spiritual needs of the family and even the child needs to be acknowledged openly. If help is needed in terms of emotional and spiritual availability, assistance from the chaplain can be asked for. One must bear in mind that it may not always be the chaplain as some families have existing religious mentors or a spiritual community they are already comfortable with, which can be tapped into.[6]

While cultural bias may be hard to completely eradicate as a barrier, having an open mindset as the palliative team is critical. Checking in with parents on their faith and spiritual practices as compared to stereotyping may be helpful in overcoming this gap.[13] If families are indeed more comfortable with a medical team member of similar faith, it may be helpful to make arrangements if possible.[15] We do

this in our institution, of note for patients of Muslim faith in view of nuances of the Islamic culture, the rest of us may not be fully cognizant of.

When dealing with difficult situations where parents are clinging to hope, communication plays a big role. Responding to emotionally strung parents and de-escalating their heightened state of tension as well as rebuilding bridges when there is a breach of trust is an effort the medical team needs to take as a part of their sensitive approach to this topic.[14] This can be done through integrating communication scenarios into training sessions and avoiding medical jargon complicit to medical objectivity.

Before discussing sensitive topics such as organ donation or autopsy, it is important to also understand the cultural beliefs of the parents. Having an open conversation and checking if they are comfortable discussing this is paramount. Families may feel upset if their child's body becomes disfigured as it affects their final rituals and this is especially true in the Asian context.[13] Discussing alternatives and not coercing them is important.

A spiritual needs assessment can be undertaken for families as a part of holistic palliative care for better rapport building and necessary but appropriate interventions[6] although one needs to acknowledge the limitation that not all parents may be readily open to this. As McNamara *et al*. stated in their paper, 'Open the door for the parents, not push them through it,' which I felt was apt as we want parents to be ready to talk to us about this delicate subject only when they are, and not feel compelled to,[15] specifically in instances where physicians are taking the lead on the spirituality discussion.

CONCLUSION

While most of the current paediatric palliative care practices or thoughts on spirituality are derived from Western ideologies, it is important to acknowledge the cultural dichotomy between East and West. Learning from other cultures and practices and incorporating them into the international paediatric palliative care guidelines would be of great help to the paediatric palliative community when dealing with cultural barriers and would help everyone render more respectful and culturally sensitive palliative care. Further studies are required to look into evidence-based improvements in the quality of spiritual care rendered in palliative care although such studies may have their fair share of limitations. However, this critical appraisal has also allowed me to learn more about how to improve the quality of spiritual care we render, and am hoping to enable my nursing colleagues and allied health as well to improve the overall holistic care for our children and families.

Author contribution

PRR contributed to the conception of and drafting of the entire manuscript.

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Declaration of patient consent

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Conflicts of interest

There are no conflicts of interest.

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