



Paediatric Palliative Care during the COVID-19 Pandemic: A Malaysian Perspective

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Abstract

Malaysia had its first four patients with COVID-19 on 25 January 2020. In the same week, the World Health Organization declared it as a public health emergency of international concern. The pandemic has since challenged the ethics and practice of medicine. There is palpable tension from the conflict of interest between public health initiatives and individual's rights. Ensuring equitable care and distribution of health resources for patients with and without COVID-19 is a recurring ethical challenge for clinicians. Palliative care aims to mitigate suffering caused by a life-limiting illness, and this crisis has led to the awareness and urgency to ensure it reaches all who needs it. We share here the palliative care perspectives and ethical challenges during the COVID-19 pandemic in Malaysia.

Keywords Paediatrics · Palliative care · Malaysia · Clinical ethics · Pandemic · COVID-19

Introduction

News of a novel coronavirus in Wuhan, China, causing deaths was reported in early January 2020. For most Malaysians, it was just a piece of news until our first four cases were detected on 25 January 2020 (Hassan 2020). The virus continued to cause an increasing number of deaths in China, and it was spreading to many other countries.

On 18 March 2020, a Movement Control Order (MCO) was imposed nationwide as announced by the Prime Minister of Malaysia (2020). Only essential services were allowed to operate. The National Security Council and Ministry of Health alongside other

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government agencies and hospitals had sprung into action to contain the potentially lethal virus. Social media and many official agencies regularly reminded the nation especially the elderly and those with co-morbidities to stay home to stay safe. The public's cooperation and appeals to altruism were emphasised.

At most hospitals, patients were contacted to postpone their clinic appointments. Non-urgent investigations and surgeries were cancelled or rescheduled. Some hospitals had diverted their patients away to prepare for patients with COVID-19. The list of designated 'COVID-19 Hospitals' in the country was published on the Ministry of Health's (2020) webpage. All efforts were focused on managing COVID-19 patients, and non-COVID-19 patients were to remain at home as far as possible. Doctors had to care for their non-COVID-19 patients with new restrictions. Palliative care patients had to adjust their expectations and negotiate their care with what providers can offer during the public health emergency.

The Director-General of Health of Malaysia appeared live daily to give a nationwide media update on the pandemic. News verified by the Malaysian Communication and Multimedia Commission were shared with the public on several cloud-based instant messaging services (Yeoh 2020). The daily update promoted a sense of solidarity amongst most Malaysians (Teoh 2020; The Edge Markets 2020a; Tam 2020).

However, the curtailment of personal and economic liberties caused by the MCO was challenged by some, and their resistance was dealt with using the law (Bedi 2020). The Prevention and Control of Infectious Diseases Act 1988 was used to enforce the restrictions (Act 342 1988). Malaysians were expected to undertake their social responsibility and accept the inconvenience for the benefit of the collective good. A mandatory 14-day quarantine was required for those who had exposure to individuals with COVID-19. Those who were COVID-19 positive regardless if symptomatic or otherwise were isolated in designated COVID-19 hospitals until they were deemed no longer infectious. Dining in restaurants was not allowed during the MCO, and physical distancing of 1 m was required when people gathered for essential activities. In multi-ethnic Malaysia, with its inherent collectivist or group-centric cultural norms, expected family visits and gatherings with elders were restricted.

There is palpable tension for policymakers and healthcare providers from the conflict of interest generated between public health initiatives and the rights of the individual. When the promises of professional duties are in conflict, the moral intuition is to ensure that the total benefits outweigh the cost and harm that arises from breaking each promise. The resource constraints to withstand a prolonged pandemic and responsibility to protect lives give the government the right to take necessary measures to contain the outbreak, to restructure healthcare systems including intensive care services and to prevent the vulnerable population from acquiring the infection and further burdening the healthcare system. Staff from other specialities were redeployed to attend to COVID-19 patients' care needs and also to support physical and mental health of front liners. Total consequentialists would justify such public health interventions maximising the total good outcome while acknowledging the required sacrifices of individuals (Giubilini et al. 2018, Sinnott-Armstrong 2019). However, a democratic government elected by the people also has a legislated and moral duty to ensure that those burdened, receive adequate support to minimise the harm from these public health measures (Humanitarian Health Ethics Research Group 2020).

For some patients receiving palliative care, these imposed restrictions added to their suffering. We share here the ethical challenges faced from palliative care perspectives during the COVID-19 pandemic, especially in the provision of care.

Provision of Palliative Care

Palliative care begins at diagnosis of a life-limiting illness through death and bereavement. It aims to mitigate suffering, be it physical, psychosocial and/or spiritual and empower patients and their families to continue a life of quality and meaning (World Health Organization 2018).

COVID-19 pandemic has changed the way palliative care is provided. The fear from exposure to the virus has prevented many patients from receiving care in hospitals. Care at home had to be modified and unusually impersonalised with personal protective equipment (PPE).

A mother of a 9-year-old boy with cancer at end-of-life was getting more pale and lethargic. She was worried about these symptoms and had hoped there was something that could be done to relieve his suffering. She had thought of bringing him to the hospital but was worried that he may acquire the coronavirus from the hospital. Her son's hospital was declared a 'COVID Hospital'. She kept him at home for as long as she could. Finally, she relented and brought him in when he looked too tired. He was seen by the palliative care and oncology team and received blood transfusions. His doctors wondered if he would have been more comfortable receiving the transfusion weeks earlier when he was first symptomatic.

The needs of patients receiving palliative care may be overshadowed by that of patients with COVID-19. For many, travelling to hospital was challenged with roadblocks meant to enforce MCO. Furthermore, the instilled fear of death from COVID-19 when one is already facing death from an illness may cause increased suffering. Self-imposed or health system restrictions may hinder patients from receiving optimal physical, psychosocial and spiritual care. While resources are stretched in a public health emergency, a just healthcare system should still be as equitable as possible (Loewy 1998; World Health Organization 2018; Humanitarian Health Ethics Research Group 2020). Patients without COVID-19 who needed treatment in hospitals should be reassured that their physical and mental health needs will also be attended to. Physicians have a professional duty of care within their institutions to advocate for all patients and ensure that the available local resources are used for maximum benefit for all during this pandemic.

Palliative care promotes good symptom control. During MCO, continued access to medications for all patients should continue. Some hospitals offered home delivery services for medications to ensure patients whose clinic appointments were postponed were not disadvantaged and could continue their medications (University Malaya Medical Centre 2020; Hospital Putrajaya 2020). These were commendable efforts to prevent interruptions to medication supply. However, patients who were on medications that cannot be delivered would be disadvantaged and will have to find alternative

measures to continue their medications within the public health restrictions imposed (Astro Awani 2020; The Edge Markets 2020b).

There were patients who needed admissions but who were transferred away from their primary hospital during this pandemic. Patients have a fundamental right to the best attainable healthcare according to the circumstances. These health provision decisions are dynamic and need to maintain a balance between social and individual benefits and harm at all times. This subjective right to palliative care is supported by the Universal Declaration of Human Rights (United Nations 1948) and is part of Universal Health Coverage (United Nations 1990; Knaul et al. 2017). However, implementation of this right should be contingent on availability and equitable distribution of resources. Doctors are duty bound to attempt to maintain as high quality of healthcare as possible even for patients who have to be transferred to another hospital. These steps to transfer patients may not ensure patients receive the highest quality of level of care, but it would have been justified as morally right as these steps protect vulnerable at-risk population from dedicated COVID-19 hospitals, as well as protect the country's resources for the community's greatest good. Medical information required for continuity of care should be transferred without breaching confidentiality. Palliative care specialists may not be available in all hospitals for patients who need palliative care. Consults with palliative care providers at referring hospital or from within the healthcare system as well as referrals to written guidance to meet the needs of patients at COVID-19 hospitals will help reduce anxiety in the chaos and uncertainties of COVID-19 pandemic (Tan and Tan 2020).

During the peak of the pandemic, community nurses were deployed to contact screen for COVID-19 in the community. These nurses had to balance the public health needs and individual patient's need for a home visit. Reduced supply of PPE for home care teams may be a trade-off when prioritising hospital needs (CodeBlue 2020). Ill patients who chose to remain at home or who were physically unable to go to hospitals and carers who could not cope with care at home on their own would have had to yield to return to hospital care.

Patients with serious illnesses who acquire COVID-19 may reach the end of their illness trajectory earlier than expected. This may happen with or without the rationing of ventilators. Acknowledging and respecting their prior decisions for terminal care may prevent non-beneficial burdensome interventions. For patients without advanced care plans, honest conversations on their values and desired care plans should be carried out when deterioration seem most likely to occur. Respect for patient's autonomy and self-determined goals of care are hallmarks of ethical and palliative care principles. During an outbreak, principles of care should not change; however, standards of care will have to be adjusted to available services and resources. Staff who have these conversations may not have had palliative care training but are in the best position to assist in these life-changing decisions. The decisions may be able to conserve scarce resources and provide patients and families with the most compassionate end-of-life care possible.

Fortunately in Malaysia, our capacity to care for COVID-19 patients has not exceeded the need even for those requiring intensive care (Soo 2020). However, the sacrifice and inconvenience caused to non-COVID-19 patients are not fully documented (Durgahyeni 2020). The ethical argument for prioritising a group of patients during a public health emergency over the other when there are scarce medical resources will need to be balanced with the burden experienced by the disadvantaged group.

Compassionate Care

Compassion arises from being responsible for others and sensitive to human suffering. Whether addressing a public health crisis or patients with palliative care needs, compassionate care may help to direct policymakers and healthcare providers to act in reducing suffering for a nation or for individuals.

There is music. It is the sound of prayers. Mother is hugging her baby boy skin-to-skin. Father is watching them on a video call from his hospital bed in the next building. He asks his wife to hold the phone next to the baby's ear as he recites the Adhan, the call for prayers. He reaches out to stroke his baby's soft hair, but his fingers simply hit the screen of the phone. Moments before, baby's elder sister had sketched her brother a picture of their house with a big heart in the middle of the picture. She showed it proudly while sitting on her grandfather's lap on a video call from home. The father continued to hum more prayers. The mother looks at her baby, he has a smile in his face, and his lips are blue. Their baby did not suffer they hope. Their baby will go to heaven. They will see their baby again.

Compassion is a valued virtue in the ethics of care and is fundamental to the healthcare professional's duty of care (Beauchamp and Childress 2013). Compassion is the combination of empathy to others and acts of beneficence in alleviating their suffering (Perez-Bret et al. 2016; Gu et al. 2017). It is the healthcare provider's fiduciary duty to ensure all patients are treated with compassion and dignity throughout their illness. A virtuous public health that is compassionate would consider all suffering as serious and undeserved; and would not solely promote the collective good at the expense of individual suffering. The extent individuals are affected by public health policies will concern a compassionate public health provider (Fahlquist 2019).

Providing compassionate care to families losing their loved one becomes even more challenging in the midst of a pandemic. Physical barriers from PPE and 'No Visitors' rules can compromise psychosocial, emotional and spiritual care. Recognition of the personhood and provision of patient and family-centred care may be easily overlooked in this pandemic.

Although critically ill children due to COVID-19 infections are uncommon, allowing a loved one to be physically present despite the rule for physical distancing is necessary for the safety and wellbeing of the child. No child should be left to die alone. Healthcare providers should also be mindful of the palliative care needs of other vulnerable groups such as the adolescent or young adults with special needs, psychiatric needs or cognitive impairment as well as those visually and hearing impaired.

Skilful communication can help mitigate the suffering experienced by patients and their families. Innovative ideas and technology can enhance communication and reduce impact of physical barriers (World Health Organization 2018; Weaver and Ibach 2019, Humanitarian Health Ethics Research Group 2020, Bowman et al. 2020). Telemedicine and remote consultations have replaced many in-person consults for patients who cannot be in hospital. With this trend, Malaysian Medical Council (2020) issued an advisory for healthcare professionals to maintain ethical, professional and legal requirements in provision of care. Healthcare providers need to differentiate between utilising telemedicine for wellness advice and telemedicine virtual consultation. Virtual consultations are for those who are already known to the physician for continuation of

care. Healthcare providers initiating treatment following visual and auditory observation without the mandatory physical examination was a permitted exception during the MCO.

Interstate and international travel restrictions may be particularly challenging for palliative care patients who have unfinished business or unfulfilled wishes that require such travel. Some patients will have to forego their possible final celebration with extended family members. Healthcare providers can facilitate by providing letters to support their applications to travel interstate (Astro Awani 2020; The Edge Markets 2020b). State approvals with army and police-led enforcements limiting travel liberties have hindered dying wishes and dramatically changed cultural norms. When travel desires are not fulfilled, surviving loved ones may have regret and guilt in bereavement. Compassionate patient-centred decisions-making and collaboration with the authorities may help avert long-term complications for bereft families.

Farewell and Bereavement

A baby with a life-limiting illness is ventilated in NICU. Her grandparents could not be physically present prior to the compassionate withdrawal of life-sustaining therapies. She is their first grandchild. Touch and kisses by close family members are no longer possible. Farewells have to be video recorded. Her grandparents wait at home for news of her death. Her father worries if his daughter will get a respectable funeral.

Multi-ethnic Malaysians commonly honour filial piety and respect for the elderly, with many medical decisions made by grandparents and elderly family members (Tan et al. 2018; Cheah et al. 2012). Location of terminal care or specific rituals often has a special meaning for patients and/or surviving relatives. Home death if desired should be facilitated as far as possible.

Despite the required physical distancing in this pandemic, ‘family presence’ can still be assisted with technology. Innovative ways for patients to connect with family members at the end-of-life will help ease the anxiety surrounding death and dying.

Funerals are important rituals in mourning and often present as opportunities for closure. During MCO, opportunities to be present at funerals are restricted to a few close relatives. If family members needed to be isolated or quarantined, separation from their loved ones with COVID-19 may have been from diagnosis to burial. Post-death procedures and screening of COVID-19 status required by public health protocols may delay funerals and cause distress to family members.

The last rituals of patients with COVID-19 will now not be ‘normal’ burials, and this transcend across all cultures and religions in Malaysia. Some of the rituals and multi-day wakes or prayers to prepare their loved ones for the next life have been modified or withheld. A body wrapped in plastic is not the norm for most religions and may leave a lasting impact on the bereft. Cemeteries are closed during MCO, and recent bereaved is not allowed to revisit the graves of their loved ones. Bereavement follow-up will be even more important during this crisis, and increased rates of complicated grief may be expected.

Attention and sensitivity to each family's needs at the end-of-life will lead to a collective health of the society that is affected directly or indirectly by COVID-19. Compassionate healthcare professionals guided by the ethics of care will be able to provide family-centred care within public health priorities.

Conclusion

In the chaos and fear during this pandemic, attention to the health and rights of the individual may be lost. Virtue ethics guides us towards our role to alleviating suffering, ensuring comfort and maintaining dignity for all our patients while being sensitive to their personal and cultural needs. It is of categorical imperative that palliative care is integrated into the health system for all patients who need it.

However, there may be occasions where conflict of interest with public health concerns will juxtapose with the needs of the individual. It is then the professional's duty to ensure there is an equitable compromise that maximises the benefits with the least harm to all, regardless of the severity of the adaptive measures that is required in a pandemic.

We hope these perspectives from palliative care will be helpful in future public health emergencies.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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