



Palliative care in the pandemic: Have human rights been preferential?

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Abstract

The skills that palliative care teams use every day at the bedside – symptom management, compassionate care, counselling of patients and families, calm and professional demeanour – are the same skills needed to treat patients with COVID-19. When it comes to humanitarian crises, the World Health Organization lists seven ethical principles that should direct palliative care. Unfortunately, many of these have been rendered impractical due to resource limitations and lack of training. Moreover, these ethical principles may guide individual patient encounters, but fall short when dealing with moral conflicts arising at a community or population level. We discuss how awareness of human rights can guide situations that call for tough decision-making in wake of this pandemic, and help us address some of these conflicts.

Keywords: COVID-19; Ethics; Human rights; Palliative care; Pandemic; Public health.

Introduction

The bedside skills utilised by palliative care teams on a day to day basis are quite similar to the ones used by teams treating COVID-19 patients. These skills include symptom management, compassionate care, counselling patients and families, and maintaining a calm and professional demeanour. As per the World Health Organization (WHO), these skills seek to improve the quality of life not only of patients facing life threatening conditions,

but also of their families. Further, they are not just for use when the sick are dying, but as soon as they are diagnosed.[1]

As Wynne et. al. (2020) have highlighted, it is a paradox that humanitarian crises and emergencies, events that are often marked by high mortality, have frequently excluded palliative care - a specialty focusing precisely on supporting people with serious or terminal illness or those nearing the end of life.[2]

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Considering that the moral dilemmas thrust upon us by the pandemic have been unsettling, agonizing and, on occasion, numbing, we discuss how awareness of human rights can guide situations that call for tough decision-making in the wake of this pandemic.

Palliative Care and Human Rights

Palliative care has been a hotbed for discussion on issues surrounding human rights. Several of these are centred around the bioethical concepts of ableism, agency and autonomy. Debates about opioid access, Do Not Resuscitate (DNR) orders, and End of Life Care are representative of some of these issues.[3-5] The connection between palliative care and human rights is exemplified by the WHO guidelines on palliative care, which state how the right to health underscores the right to palliative care.[6] Palliative care is also recognized in the UN Committee on Economic Social and Cultural Rights' (CESCR) authoritative interpretation of the right to the highest attainable standard of health (General Comment 14).[7]

Pitfalls in the Pandemic

The WHO released a guide two years ago integrating palliative care as a key ingredient in the response to humanitarian crises. They listed seven ethical principles that must direct palliative care: respect for persons, non-maleficence, beneficence, non-abandonment, double effect, justice, and solidarity.[8] While these principles may guide individual patient encounters, they fall short when dealing with moral conflicts arising at a community or population level.

These conflicts include those arising from resource limitations that have rendered many of the above principles impractical in the past few months. Instances of shortage of essential drugs, the need to ration ventilators, isolate patients, triage admitted patients, and a shortage of personnel have

often made us wonder if human rights can be justified as preferential.[9-11]

While it may seem obvious in hindsight, Arya et. al. (2020) predicted how palliative care services would be needed across many different care settings, including in intensive care units, hospital wards, emergency departments, and in long-term care, and how the pandemic would strain the healthcare system beyond capacity at the outset.[11] Unfortunately, the training of healthcare workers in palliative care has not kept up with this prediction. Indeed, the lack of training of healthcare workers in the above settings have only compounded the existing difficulties in upholding the ethical principles embodied in palliative care. Palliative care, after all, is an approach to be adopted by all practitioners. Expecting doctors and nurses to provide care in a large scale humanitarian crisis with little or no training in triage, symptom management, end of life care, and counselling is bound to be challenging.

There is also an emotional cost that comes with the compromise of human rights. Patients and family members cannot be by the side of each other. They may have to make important decisions and sacrifices against the uncertainty that is part of this illness. Moreover, they often face stigma and discrimination owing to misconceptions of the public. Wynne et. al. (2020) highlight how healthcare professionals, emergency services staff and humanitarian workers, as well as organisational leaders and policy-makers are shaken by powerlessness, guilt and fear from witnessing COVID-19.[2] They propose a population level bioethics approach to address these concerning issues. This proposal is based on the fundamental contention that different segments or subgroups within a society will require varying 'right actions' due to differential access, availability, and opportunity to use resources.[12,13]

Dealing with Uncertainty: A Human Rights-centric Approach

Medicine seeks to realign its practice and incorporate a more holistic and patient centred approach. Perhaps an attempt to transition from a 'biomedical' to a 'biopsychosocial' (BPS) epistemology as articulated by George Engel in 1977 is required.[14] A study by Trotter et. al. in 2009 reported that the BPS model was associated with fewer stress reactions amongst primary care physicians.[15] This is important to note. Not only does the BPS model mark a shift from a reductionist to a more holistic approach in medical practice, it also arms the clinician with an important trait - the ability to deal with the stress of uncertainty that is part and parcel of medical practice. Palliative care as a discipline has adopted the BPS model, making it an appropriate tool against the uncertainty of the pandemic.

PANEL Component	Examples of measures that can be implemented
Participation	<ul style="list-style-type: none"> Involving patients / families / surrogates in critical decisions through telemedicine or video calls SPIKES* protocol when conveying difficult decisions Reflective listening of concerns.
Accountability	<ul style="list-style-type: none"> Discuss available evidence and rationale behind management plans Documentation to maintain transparency
Non discrimination and Equality	<ul style="list-style-type: none"> Clinical factors (illness severity, comorbidities) to be considered in triage decisions Old age, financial status, disability unrelated to condition should not influence triage Egalitarian approach in identical clinical scenarios while rationing resources (e.g. First come first serve basis [17])
Empowerment	<ul style="list-style-type: none"> Equal say in establishing goals of care Accommodations for patients with disabilities (family member at bedside) Compassionate care if treatment withdrawn
Legality	<ul style="list-style-type: none"> Know legal basis to determine prioritization (e.g. not unlawful to withhold Cardio-Pulmonary Resuscitation if post resuscitative intensive care is medically contraindicated) [17] Provide oversight authority in triage decisions Mechanism to appeal for deviation from protocols

*SPIKES: Setting, Patient perception, Invitation, Knowledge, Emotion, Summary and Strategy

Table 1: Suggested measures using a human rights based approach (PANEL)[16] for palliative care practice during the pandemic

As palliative care teams continue to provide competent care to those 'individual' patients affected by the pandemic whilst upholding 'individual' human rights, it is imperative for all of us to work on the rights of the 'collective' and ensure better preparedness and sustainability in dealing with this complex situation. The Human Rights Based Approach is underpinned by five principles, also known by the acronym PANEL - Participation, Accountability, Non discrimination and Equality, Empowerment, and Legality.[16] Table-1 lists examples of measures relevant to palliative care in the pandemic. As the table shows, the acronym - PANEL - effectively captures the key elements of a human rights based approach in addressing issues.

We do not wish to provoke a moral argument based on the ideals of utilitarianism. We hope, rather, to address practical issues that may help guide physicians while discharging their clinical duties. These include addressing 'trade-offs' that arise when dealing with the rights of the 'collective' as opposed to individual rights.

The examples in the table illustrate how these principles can preserve the dignity of our patients against difficult trade-offs. It is important to highlight that these issues are not limited to palliative care specialists, but involve all healthcare workers across all specialties. As Laura Kolbe of Weil Cornell put it, "All doctors are palliative care doctors now." [18] Even otherwise, the first ever global resolution by the World Health Assembly in 2014 called for the integration of palliative care as a core component of health systems.[19] Training of students/residents and capacity building of professionals shall ensure they are equipped to address these ethical conflicts and are sensitive to the nuances of palliative care practice. Lastly, we also recommend providing psychological support to both patients and healthcare workers who may be burdened with guilt owing to

the difficult decision-making that has been part of the pandemic response.

Conclusion

Utilising a human rights based framework in decision making ensures that we preserve the dignity of patients even as we face challenging decisions, moral dilemmas and difficult trade-offs. It is also important to integrate this approach within all healthcare teams, and not just in palliative care. After

all, the pandemic has assured that healthcare teams across different settings have had to familiarise themselves with the principles of triage, of rationing, of compassionate care and so on. Lastly, considering the unprecedented issues faced during the pandemic, a human rights framework is imperative for articulating and organizing sustainable advocacy in the interest of both patients and providers.

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