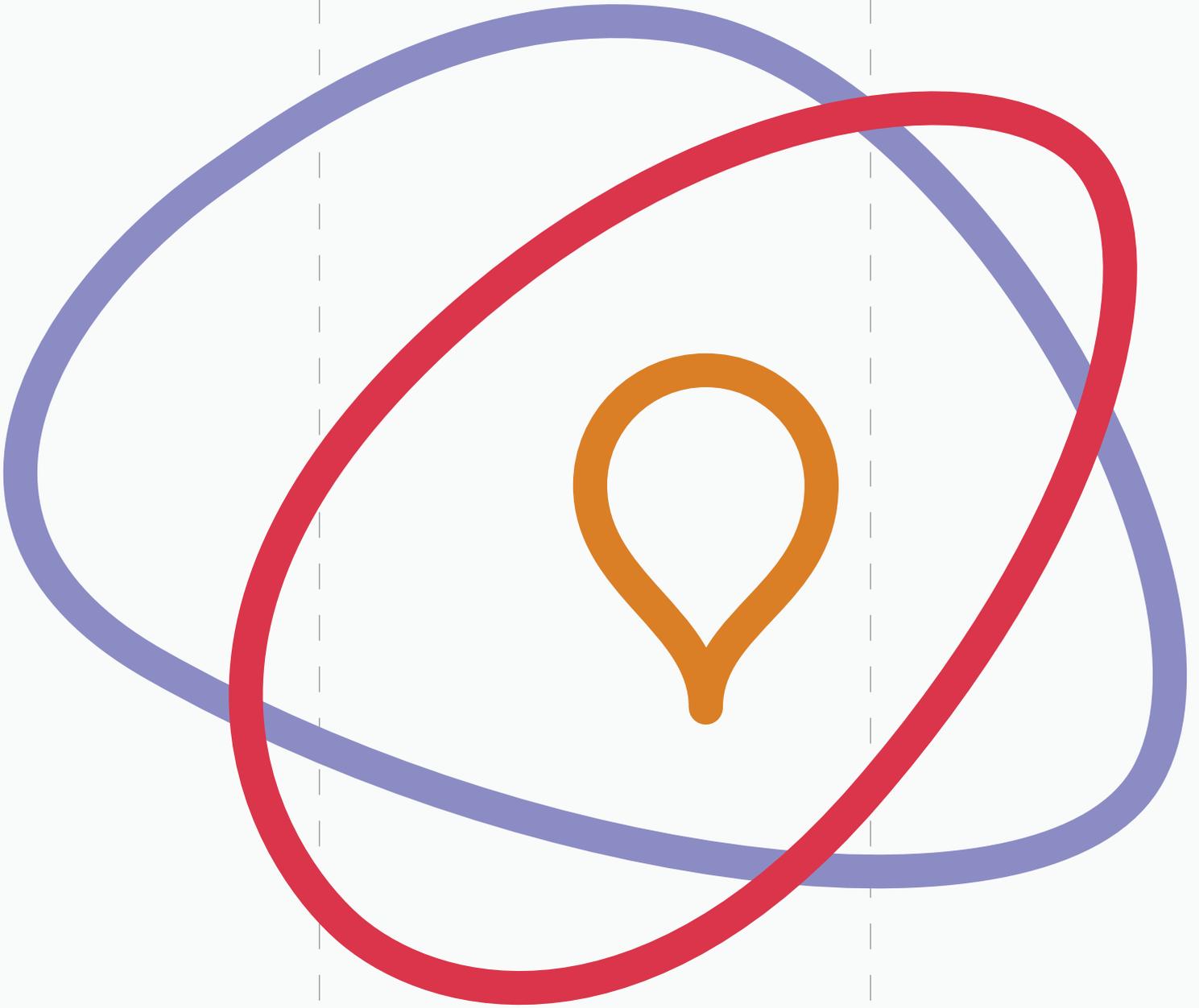




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# PALLIATIVE CARE IN HUMANITARIAN CRISES: INNOVATION OR RADICAL RECLAIMING OF ROOTS?

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## **Working Paper 002**

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# ABSTRACT

Palliative care and humanitarian action share fundamental goals to relieve suffering and uphold dignity; and both hold an ethical root in the recognition of our common suffering in illness and dying, our compassionate action in response to suffering, and our common humanity. The parallels in goals and ethos should make universal application of palliative care in humanitarian crises a norm, but in humanitarian practice today this is not the case.

There is growing consciousness of the imperative to integrate palliative care into humanitarian response. Compassionate palliative care is steeped in humanitarian history, norms and ethics. 'Small but potent' acts of compassion are a profound and far-reaching element of palliative care response that can be delivered no matter how scarce the resources. In addition to meeting a neglected need, the broader practice of 'small but potent' acts of compassionate palliative care may serve to remind humanitarian actors of the very essence of a humane response and offer a radical reclaiming of the roots of humanitarianism.

## Introduction

*Last year, I travelled to Somalia with an international humanitarian organisation where I witnessed the devastation that decades of prolonged drought, famine, violence and insecurity have wreaked on the health of its communities.*

*I visited a hospital caring for malnourished children. I was taken to a room where a young girl lay on a bare table. The girl was screaming in pain, crying out for her father. She had a very visibly swollen and red-hot groin having endured female genital mutilation (FGM) some days before. Her entire body was also in tonic spasms – she was suffering from tetanus as a result of the dirty metal implement used to perform the FGM. She was in absolute agony, but there was no pain or symptom relief in sight. Her father stood in distress by her side, lifting her up in an attempt to ease her pain each time she screamed out ‘Papa’.*

*I learned that the girl was 10 years old – the same age as my daughter at home. I went close to the girl as she screamed, lent over to her, touched her hand and whispered gently in her ear a simple but soothing ‘shh, shh, shh’. The girl immediately stopped her crying and turned her head towards the sound, searching for my face. Her body relaxed and for some moments, she became still and calm, seemingly comforted, if only fleetingly, by my warm touch and my soft voice.*

*We left shortly after, and the young girl died the next day.* Personal communication with Nichola Krey, humanitarian practitioner, 2019

Humanitarian action is concerned with a host of helping endeavours in times of crisis, mostly within resource-poor settings. Palliative care is a (traditionally Western) specialist branch of healthcare that deals with the comprehensive support and comfort (physical, emotional, social and spiritual) of the chronically or seriously ill and dying, and bereavement care for families after a person has died (Gomez-Baptiste and Connor, 2017; Knaul et al., 2018). The two fields share immense common ground: both make universal claims about the need for humane care of suffering individuals and of the value and dignity of human life; and both hold an ethical root in the recognition of our common suffering in illness and dying, our compassionate action in response to suffering, and our common humanity.

In one way or another, some of the central aims of palliative care have featured throughout the history of humanitarian response. The parallels in goals and ethos should make universal application of palliative care in humanitarian crises a norm; but in humanitarian practice today, this is not the case.

This conceptual paper considers the current state of palliative care in humanitarian response. It explores what compassionate responses to seriously ill and dying people look like in the context of humanitarian action. While the introduction of palliative care into modern humanitarian response is a welcome innovation, this paper suggests

that it is the very antithesis of an innovation that is technical, shiny and new. Rather, palliative care is steeped in humanitarian history, norms and ethics. In addition to meeting a neglected need, the broader practice of palliative care may also serve to ground and remind humanitarian actors of the very essence of a humane response. This work is based on critical reading of published papers, reports and narrative accounts of the lived experiences of those working in both palliative care and humanitarian contexts.

## A growing consciousness of need

Last year, the Lancet Commission on Palliative Care and Pain Relief published its landmark report on the ‘access abyss’ for the poorest people in the world who live and die in extreme suffering (Knaul et al., 2018). More than 61 million people experienced ‘serious health-related suffering’ in 2015, including 25.5 million people who died without receiving palliative care (ibid). These numbers are predicted to increase rapidly over coming decades due to rises in diseases such as cancer and dementia, with the greatest increases in low-income countries (Sleman et al., 2019). This means a far greater number of people will suffer before, and as, they die.

Situations of armed conflict, forced migration, disease epidemics and natural disasters cause suffering on a mammoth scale. Increasingly complex and protracted conflicts are challenging and reshaping the way humanitarian action is understood. Humanitarian organisations are more successful in saving lives; but the needs of those who would benefit from palliative care often go unmet. Although little is known about the practice of palliative care in humanitarian contexts (Nouvet et al., 2018; Schneider et al., 2017), there is at least a growing consciousness of need (Powell et al., 2017; Smith and Aloudat, 2017).

There are different humanitarian scenarios where palliative care warrants consideration: in protracted crises where pre-crisis care for patients with life-limiting illness is interrupted or needs are exacerbated; in mass casualty events where resources are engulfed by acute injuries and individuals are triaged according to survival likelihood; in epidemics with high mortality; and in camps for refugees and displaced people (Powell et al., 2017).

Recent and current Ebola epidemics have brought the urgency of palliative care to the attention of international humanitarian actors. For many Ebola patients, palliative care is realistically all that can be achieved (Redfield, 2013). Cancer care in humanitarian emergencies such as Palestine, Iraq, Syria and Yemen typify a growing trend towards chronic disease care that demands attention alongside injury, infectious disease and malnutrition (Spiegel et al., 2014). In Yemen, deaths have risen due to interruption of medical treatment and supplies for chronic disease care – ‘cancer patients in Taiz are waiting for either the shelling or the cancer to kill them’ (Al-Sakkaf, 2016).

## Challenges and solutions for integrating palliative care into humanitarian response

Mounting concern over the neglect of palliative care in humanitarian response, mostly led by Western practitioners, has raised a number of challenges for the integration of palliative care as a specialist discipline.

Firstly, palliative care tends to be beyond the convention of modern humanitarian practice. There is a bias of curative biomedicine over aspects of compassionate care to relieve suffering (Bogucki, 2009). The superiority of saving lives also takes precedence over palliation. This is propped up by global health metrics – for example, mortality rates – which place the qualitative aspects of human lives, relationships and suffering in simple counting terms (Calhoun, 2008). The changing nature of disease and long durée of crises is blurring the definition of conventional humanitarian emergency practice (Redfield, 2013; Schneider et al., 2018). Humanitarian organisations are less experienced in managing chronic conditions with long disease trajectories that are steeply increasing the number of patients who need palliative care.

Secondly, palliative care is beyond the capacity of humanitarian resources and systems. Triage practices in humanitarian action focus little on what to do for those who will die despite best efforts or who are relegated to die by triage (Rosoff, 2010; Wilkinson, 2012). Bereavement care to manage raw grief in dying and death is seldom provided. The limits of resources are major impediments to palliative care options (Hunt et al., 2018; Schneider et al., 2018).

Third, palliative care is beyond the competence of today's humanitarian actors. Even where support is expressed for incorporating palliative care into humanitarian response, there are a lack of policies, guidelines and training to support them to do so (Nouvet et al., 2018; Powell et al., 2017; Schneider et al., 2018; Smith and Aloudat, 2017).

Finally, palliative care must consider cultural values and differences. Diversity in values of illness, death and dying are a challenge for the implementation of palliative care. Existing interventions have been developed within a Western frame and may not transfer easily into humanitarian settings.

The WHO guidelines on *Integrating Palliative Care and Symptom Relief* into the response to humanitarian emergencies and crises respond to the emergent call for guidance (World Health Organisation, 2018). The guidelines outline an essential package of medicines, equipment and human resources to alleviate pain and suffering which may be delivered by doctors, nurses, psychologists, social workers, spiritual leaders or community health workers trained in basic palliative care. One of the clearest entreaties of the guidelines is that fast-acting preparations of morphine be made available for any seriously ill person with moderate to severe pain or terminal shortness of breath.

Palliative care is now also included in the latest edition of the Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response (The Sphere Project, 2018). These two documents alone signify a breakthrough in raising the profile of palliative care as a vital technical, specialist innovation in modern humanitarian practice.

## The complementary elements of palliative care

Palliative care as a specialist discipline is tremendously important to relieve the suffering of anyone with a chronic, serious or terminal illness. This includes not just the provision of essential medicines for pain and symptom relief, but efforts to improve the availability of opioids through policy and legislative change. Only 0.03 per cent of the world's opioids are distributed to low-income countries (Knaul et al., 2018). It is a laudable goal to ensure such medicines are available to alleviate physical suffering in humanitarian crises.

But is there a more impactful aspect of palliative care that is in plain sight or has perhaps been lost from sight in humanitarian contexts? Let us return to the story of the young girl dying from tetanus. In that moment, what this poor girl needed was treatment alongside comprehensive palliative care: she needed tetanus antitoxin, antibiotics and admission to an intensive care unit; and she needed urgent pain and symptom relief, such as diazepam to control muscles spasms and morphine to induce sedation. Of course, none of this was available in the Somalian humanitarian crisis. What could be done? And what is palliative care in this scenario?

Comprehensive palliative care is inclusive of medical and clinical interventions to relieve pain and symptoms; psychological, social or spiritual practices (including evidence-based) delivered by trained professionals; and “small but potent” compassionate acts of caring and comforting. All are valid and all are mighty. Kleinman has expressed concern that the current biomedical system tends to replace allegedly ‘soft’ (therefore devalued) psychosocial and spiritual concerns of illness with the scientifically ‘hard’ technical quest for the control of physical pain and symptoms (Kleinman, 1988). The ‘small but potent’ and unrehearsed act of comforting the girl dying of tetanus may be almost the antithesis of innovation or technical intervention. This should not discredit its immense power in alleviating the girl's intense anguish and loneliness, if only fleetingly.

Notwithstanding the importance of access to pain relief – and recognition that such access is a serious impediment to the provision of palliative care in humanitarian crises – sometimes, doing *something* is found not in elaborate preparation, but in small things which reach out to the sick and lonely person and bring them back to us (Cassell, 2004a). A cup of tea, a blanket, a piece of bread, a genuine attention, a humble solicitude: ‘Very small things indeed’, writes humanitarian doctor Paul Bouvier, ‘so derisory that they rarely dare to appear in reports, accounts and media

articles...yet, such small things sometimes represent a substantial part' (Bouvier, 2012: p.1538).

These 'small but potent' acts of compassion may be against the grain of technical innovation but are nonetheless imperative in dire humanitarian situations when the drugs, resources and expertise just are not there. They are also central to the relief of all aspects of suffering, sometimes just as important or more so than the relief of physical pain. Lastly, the concept of 'small but potent' acts of compassionate response to suffering is not new in humanitarian action; it may in fact be a trigger for reclaiming the roots of modern humanitarianism and age-old traditions in alleviating suffering.

Without efforts to explore the role of 'small but potent' acts of compassionate palliative care for the relief of suffering, they may be rendered a mere afterthought to technical intervention.

### **When the drugs and expertise are not there**

What happens when the ideals of comprehensive palliative care are thrust into the realities of humanitarian emergencies - where resources are finite and societal needs loom large? Or when humanitarian actors perceive the required action to be beyond the scope of their remit or expertise? The practical business of integrating palliative care becomes more convoluted amidst complex and sometimes dangerous conditions. This is 'The humanitarians' tragedy,' when 'human ideals fail to match the realities of the human condition' (de Waal, 2010: p.S130). How does one 'maintain a commitment to, and respect for, human dignity, even in the most austere of circumstances, while simultaneously recognising the inevitable limitations of certain forms of programmatic response'? (Smith, 2018: p.18). The call for palliative care in humanitarian situations throws wide open the inherent tensions between humanitarian ideals and realities.

The humanitarians' tragedy is stark across crises settings. The catastrophic Nepal earthquakes created overwhelming acute death and injury; but most demands for healthcare arose from interruptions in treatment of chronic illnesses, and the collapse of health infrastructure, sanitation systems and pharmaceutical supplies, exacerbated by border restrictions and delays of essential medicines (Aryal, 2015). Such interruptions in access to drugs and basic supplies such as food, water and fuel have resulted in deadly consequences across other disasters, for example, Hurricane Maria in Puerto Rico (Fink, 2018).

In a recent unpublished study from Gaza on availability of pain relief for surgery following gunshot wounds, the surgeons did not have so much as paracetamol, let alone stronger analgesia such as morphine (personal communication, Lancet Palestinian Health Alliance Conference, March 2019). Currently, fifty-two per cent of life-saving medicines in Gaza are at zero stock - meaning, there is less than one month's supply left or no medicines at all to support the needs of ill Gazans (Medical Aid for Palestinians, 2019). In 2016, Elizabeth Hoff, WHO

Representative in Syria lamented on the lack of medicines and medical equipment reaching civilians in conflict: 'if they are not properly treated, they cannot even die in peace because they are not receiving the necessary pain killers and palliative care that is needed in many of the besieged areas' (UN Department of Public Information, 2016).

While some authors contend that palliative care in humanitarian settings demands sophisticated clinical expertise and technologies for pain and symptom control (Bogucki, 2009), humanitarian actors reflect on 'small but potent' acts of compassionate palliative care: 'In some instances, proper intervention is not an operation or primary disease control but to give comfort and restore hope. Palliative care can mean giving a man a stick to bite on while his leg is amputated, touching the shoulder of a mother whose child was buried under the collapse of the school building, or bringing a smile to the face of a child who has not smiled for 6 months' (Huffman, 2011: p.67).

When all the practical offerings of comprehensive palliative care - medicines, equipment, beds, needles, catheters - cannot be sourced because of grim or dire circumstances, sometimes 'small but potent' offerings of compassion and comfort are all we have.

### **Suffering and the art of compassionate care**

What makes 'small but potent' acts of compassion so fundamental to alleviating suffering? Alleviating suffering is what humanitarian actors are called to do; and it is the central mission of palliative care.

Physical pain is the most commonly identified source of suffering. Although suffering may attend pain, the two terms have distinct definitions and one can arise without the other. For French philosopher Paul Ricoeur, 'suffering is not defined solely by physical pain, nor even by mental pain, but by the reduction, even in the destruction, of the capacity for acting, of being-able-to-act, experienced as a violation of self-integrity' (Ricoeur, 1992: p.190). Suffering is an intensely personal and sometimes social experience; and patients and families often do not distinguish between physical and non-physical suffering particularly in dying (Cassell, 2004a; Cassell, 2004b). One of the key goals of palliative care as a medical speciality is the control of avoidable pain in dying. Yet in some contexts and cultures, having a pain-free illness or death is afforded lesser priority than non-physical needs such as intimate relationships and attending to spiritual suffering (Mistry et al., 2015; Sinclair et al., 2016; Zaman et al., 2017).

A humane response to suffering gives rise to compassion. Saint Thomas Aquinas proposed that compassion is at once an emotion and a virtue in response to suffering: we share in the suffering of another and subsequently have a desire to act (Ryan, 2010). Ricoeur sees our response to the suffering of others as compassionate and life-affirming - when we demonstrate 'solicitude' for others, we not only help them and share their pain, but we affirm our own self-worth as humans. This mutual exchange is found in

the moment when we recognise our common humanity with a suffering other. It is 'an authentic reciprocity in exchange, which, in the hour of agony, finds refuge in the shared whisper of voices or the feeble embrace of clasped hands'; and a process of 'shared admission of fragility, and finally of mortality' (Ricoeur, 1992: p.191-2).

For French philosopher Simone Weil, this compassion starts with a genuine attention which leads to empathic witnessing and listening (Miles, 2005). Attending to a person's story – their illness narrative – can create meaning of suffering and be of immense therapeutic value (Cassell, 2004a; Kleinman, 1988).

For contemporary ethicist Raimond Gaita, genuine compassion is an example of 'pure love' and common humanity (Gaita, 2004). Authentic acts of compassion and love shine light on the profound sense of irreplaceable preciousness of those being comforted – their 'power to reveal the full humanity of those whose affliction had made their humanity invisible' (Gaita, 1999: p.20).

This compassion and love which arises in response to suffering is central to the humanitarian principle of humanity. Humanitarian action is a compassionate response to severe suffering arising from violence, disaster or epidemics, which, 'At its best, it is a very practical affirmation of the value of human life and its unique character in each human person' (Slim, 2015: p.2):

The ground of ethics in humanitarian action is a profound feeling of compassion and responsibility towards others who are living and suffering in extremis. It is a feeling of identification and sympathy that demands some reasonable and effective action as a response to suffering. Humanitarian feeling can be born out of a warm glow or a cold shiver. It may burst from the chill horror at outrageous cruelty and a strong passion to stop it; or it may spring from the depths of love and a burning desire to care for someone. It may arise between the two in a sense of sadness at suffering, and a desire to encourage and build up. (Slim, 2015: p.26)

Palliative care holds the same values to be true. According to Oliver Sacks, the humanistic doctor will move between two worlds: the 'classical world' with its 'objective description of disorders, mechanisms, syndromes'; and the 'romantic world' – an 'empathic entering into patients' experience of illness' which requires imagination, empathy and understanding (Sasser and Puchalski, 2010: p.939). Here, 'the humanistic clinician enters the world of the patient and expertly surveys the terrain for all possible sources of suffering, poised to tap skills biomedical and beyond, to facilitate healing and to serve as empathic witness to the illness experience' (ibid). Kleinman's stories validate that the work of the health professional in caring for chronically ill patients is to be 'there in the experiential realm of suffering together with his patient and members of the family...the experience of the healer can be a quest for a kind of human wisdom, a model of forbearance and courage, a form of goodness, a lesson in the essentials of humanity' (Kleinman, 1988:

p.276). It is 'small but potent' acts of compassion which play a primary role in restoring dignity and relieving suffering.

## 'Small but potent' acts of compassion

### What do they look like?

Compassionate acts can be exhibited by human touch, posture and body language, thoughtful listening, empathic witnessing, exploring spiritual questions or merely sitting in silence providing presence (Cassell, 2004a; Kleinman, 1988; Sinclair et al., 2016). They may constitute deep relationships between patient and carer; or be fleeting moments in time and be delivered by strangers (as with the dying Somalian girl) (Bramley and Matiti, 2014). They are often spontaneous and improvised, integral to the carer as a compassionate human, unbound by the professional role they fill. Supererogatory acts – those which 'go above and beyond', 'go the extra mile', are not part of job descriptions and are non-remunerated – may also constitute 'small but potent' compassionate acts which have great impact in relieving suffering (Dawson-Goodey, 2011; Sinclair et al., 2016; Sinclair et al., 2017).

Palliative care and humanitarian actors also need to be humble enough to accept that some forms of suffering cannot be mended; these forms of suffering may be intrinsic to the illness process or brought about by social context. The ability to 'sit with suffering', to bear what is unbearable, and to acknowledge and validate it with presence takes fortitude but is sometimes some of the best and only care that can be provided (Rattner and Berzoff, 2016).

Humanitarian actors see value in sitting with a suffering person. Bouvier writes on 'brief notes about very little things' (Bouvier, 2012: p.1530) and 'drops of humanity in dehumanised places' (p.1542). Slim draws on Ricoeur's solicitude and Weil's attention to contend that 'intimate deliberation' with suffering individuals – involving personal discussions, empathic listening, imagining and intimate relationship-building – should be at the heart of humanitarian action and the frontline of humanitarian ethics (Slim, 2015). Listening to a person's narrative and accepting mutual fragility can create wondrous relationships which embody the most profound humanitarian response.

Where palliative care has been explored in humanitarian response, bearing witness and accompaniment – a sense of not being abandoned – have been described as essential parts of care more important than painkillers to some local health workers (de Laat et al., 2018; Schneider et al., 2018). Accompanying the ill person can help them cope with a lack of therapeutic options: 'If you cannot do anything against the pain, [be there]' tells an Iraqi nurse, 'They [the patients] will feel that they are not left alone. That is most important' (Schneider et al., 2018: p.5). A humanitarian doctor describes a decision to pray with a patient despite not being religious: the act of accompanying the patient in prayer 'basically said I'm with you' (Hunt et al., 2018: p.6). Enabling patients

to maintain connection with family was particularly important in the West Africa Ebola crisis where even the preciousness of human touch in dying needed to be experienced through the barrier of protective clothing (Downing, 2014; Webster, 2015; Wilson, 2015; Wolz, 2014).

The power of presence is supported in the poignant writing of Henri Nouwen:

But what really counts is that in moments of pain and suffering, someone stays with us. More important than any particular action or word of advice is the simple presence of someone who cares. When someone says to us in the middle of a crisis, 'I do not know what to say or what to do, but I want you to realise that I am with you, that I will not leave you alone,' we have a friend through whom we can find consolation and comfort. (Nouwen et al., 2006).

Returning to Gaita, it is 'small but potent' acts of compassion which reveal the inalienable dignity of those poor souls who are suffering and have lost everything else (Gaita, 2004). Gaita reflects on a story from Primo Levi about the wreck of a man Ladmaker who is dying from typhus in a Jewish concentration camp just at the brink of liberation, and the small but supererogatory act of Charles:

Charles climbed down from his bed and dressed in silence. While I held the lamp, he cut all the dirty patches from the straw mattress and the blankets with a knife. He lifted Ladmaker from the ground with the tenderness of a mother, cleaned him as best as possible with the straw taken from the mattress and lifted him into the remade bed in the only position in which the unfortunate fellow could lie. (Gaita, 2004: p.xvi).

Gaita wonders at the goodness of the act, and the spirit of compassion in which Charles performs it: 'the wonder of what Charles did is that he responded fully to Ladmaker's degradation, saw fully the depth of it, whilst affirming Ladmaker's undiminished humanity' (Gaita, 2004: p.xvii). The kind of compassion expressed by Charles, as for the humanitarian colleague who saw that the dying Somalian girl was as human as her own daughter, demonstrates the very essence of what it means to be a humanitarian and to share in the suffering of another.

### Who can deliver them?

'Small but potent' acts of compassion can be provided without specialist training and with little clinical knowledge by non-specialist doctors, nurses, lay health workers, psychosocial carers, spiritual leaders, and even family members (Cherny, 2006; Downar and Seccareccia, 2010; Wilkinson, 2012).

There is an increasing distinction between 'specialist' and 'generalist' palliative care (Zaman et al., 2017). The former encompasses complex pain and symptom management using advanced skills, often in settings dedicated to palliative care. The latter is a collection of skills which can be practiced across different settings by people with differing levels of training. There is a potential

clash of cultures when specialist providers of palliative care in Western countries develop guidelines for non-Western contexts (ibid). Specialist palliative care, centred around the Western hospice model which developed as a discipline throughout the 1960s-1980s, has set the standard of caring for people needing palliative care (Abel et al., 2013). But, as Dr Kumar argues: "Despite attempts from various corners for more than three decades, globally, palliative care is accessible to only less than 8% of the needy today...we are unlikely to achieve any meaningful coverage ever if we continue to take the conventional track" (Zaman et al., 2017: p.75). For Kumar, an approach to increasing the coverage of palliative care services globally is to be found in a model of community participation.

Modern humanitarianism's 'localisation' agenda paves the way to consider the role of local responders in palliative care provision. Even before 'localisation' entered the vernacular of humanitarian debate, Bornstein and Redfield had highlighted in the wake of the devastating Haiti earthquake: 'the far less publicised or enumerated acts of care undertaken by Haitians – the vernacular world of neighbours, relatives, and passersby that plays a central role in responding to a disaster, as it does in everyday life. With bare hands and minimal tools Haitians rescued far more of their own than any of the specialised teams with their elaborate equipment' (Bornstein and Redfield, 2010: p.252). Later, Slim observed, 'As surely as this person is suffering, it is equally certain that someone will be trying to help them' (Slim, 2015: p.1).

### Radical reclaiming of roots: remembering the humanity of humanitarian response

Compassion needs to be absorbed and believed as an emotion and a virtue if palliative care is going to take hold in humanitarian practice. This does not require technological or new innovation but the very opposite. First, it requires a historical recollection of what once constituted the alleviation of suffering.

The central goals of palliative care once featured strongly in society and in humanitarian response. In the 19th century, long before the advent of specialist palliative care, society was preoccupied with suffering. Hospices to comfort the dying flourished. The doctor William Munk published a hallmark treatise in 1887 on 'easeful death', describing practical, spiritual and medical care for the dying (Clark, 2016). The formal humanitarian system owes much credit to Henry Dunant's brutal, yet compassionate account of the Battle of Solferino in 1859 (Dunant, 1959). Dunant, stumbling across the battlefield as a travelling businessman, tried to relieve the suffering of wounded soldiers; and proposed that relief societies be established to assure more humane care of the wounded during warfare. This recommendation would lead to the establishment of the International Red Cross and Red Crescent Societies and the creation of the first Geneva Convention – the building block for international humanitarian law (ibid).

As a seminal document for modern humanitarianism, Dunant's *Memory of Solferino* depicts harrowing suffering (Dunant, 1959). In response, juxtaposed against the urgency of the crisis, Dunant describes moments of tenderness, suggesting compassionate care manifest in accompanying and soothing the dying is the keystone of humanitarian action:

"I don't want to die!" shouted a Grenadier of the Guard fiercely...He fully realised that his hours were inexorably counted, and strove and struggled against that grim uncertainty. I spoke to him, and he listened. He allowed himself to be soothed, comforted and consoled, to die at last with the straightforward simplicity of a child. (Dunant, 1959: p.66)

The principles which emerged in this process remain the guiding principles for humanitarian action today: the overall goal of humanity – to protect life and health and alleviate suffering wherever it may be found – and impartiality – its universal and non-discriminatory application. The principle of humanity holds that humanitarian actors should help everyone suffering from the effects of conflict or disaster, leading to what Slim calls 'a radical equality' in humanitarian action (Slim, 2015: p.56). To be alive is the stuff of physiology, but to live a life where suffering can be eased requires that human relationships and spirituality are treasured.

Yet discernment of why it is good to practice the principle of humanity seems to have gone awry (Slim, 2015). As the number, scale, duration and complexity of crises throughout the world intensifies, clear definitions of the scope of humanitarian action are increasingly murky; and criticisms abound that the sector is no longer fit for purpose (Bennett, 2018; Spiegel, 2017). Medical humanitarianism is failing to meet health needs (Colombo and Pavignani, 2017). A 'broken' humanitarian system (Spiegel, 2017) is prompting calls for an urgent refocus on humanitarian purpose and ethos as one of 'solidarity, empathy and human connection' (Bennett, 2018: p.5).

Alongside this, medical science's fixation with clinical intervention has relegated historic efforts to relieve all manifestations of suffering in illness and death. Even the Lancet Commission's framework to measure the global burden of suffering focuses on physical and psychological suffering to the neglect of spiritual and social suffering: the responsibility for which the Commission considers outside the remit of the health system (Knaul et al., 2018).

The power of 'small but potent' acts of compassionate palliative care could serve to remind the humanitarian sector of the art of caring, the act of standing with and alongside, and of our common suffering in illness and dying and our common humanity. In this way, 'small but potent' acts of compassion could offer a radical reclaiming of the roots of humanitarianism and a path through which to recover a sense of wonder at the preciousness of every human. This power should not be underestimated.

## Conclusion

Rising chronic illness and increasingly complex humanitarian emergencies are creating an urgent imperative to integrate palliative care into the humanitarian response. Encouragingly, there is a growing consciousness of this imperative. But rolling out an essential package of specialist palliative care, whilst innovative and immensely important, won't be sufficient. The resources are not always available; and it does not cover all aspects of human suffering in illness and dying which are individually and culturally conceived. If viewed purely as a new technical addition, palliative care will not have a transformative effect in alleviating suffering for seriously ill and dying people. Notwithstanding the power of 'small but potent' acts of compassionate palliative care, such acts are rarely afforded priority. Amidst a sector wowed by Apps, gizmos and gadgets, how can the importance of humane acts which run counter to technological innovation be raised?

We need to think again and to think radically – not in the sense of shiny new interventions and innovations, but in the sense of going back to the roots of humanitarian ethos and ethics in alleviating suffering and remembering our common humanity. 'Small but potent' acts of compassion are intricate, multifaceted and hard to define – small, yet can make a defining, life-changing, death-changing difference both to the people that receive them, and the people that provide them. What defines them is it that no matter how scarce the resources, there is opportunity to enable them; they may often come from strangers; they may be unexpected and unprescribed; and they make a big difference. They are not flashy advances in the way of artificial intelligence or blockchains – sometimes they are an act of 'stillness' of being with the affected amidst the urgency of crises. But they are profound and far-reaching; and will require immense courage and leadership from the humanitarian sector to get behind.

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