

Upside down solutions: palliative care and COVID-19

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ABSTRACT

The current COVID-19 pandemic is unprecedented and requires innovation beyond existing approaches to contribute to global health and well-being. This is essential to support the care of people at the end of their lives or who are critically ill from COVID-19 or other life-limiting illnesses. Palliative care (PC) is centred on effective symptom control, promotion of quality of life, complex decision-making, and holistic care of physical, psychological, social and spiritual health. It is ideally placed to both provide and contribute to care for patients, families, communities and colleagues during the pandemic. Where recovery is uncertain, emphasis should be on care and relief of suffering, as well as survival. Where healthcare resources and facilities come under intense pressure, lessons can be learnt from models of care in other settings around the world. This article explores how the field can contribute by ensuring that PC principles and practices are woven into everyday healthcare practice. We explore alternative ways of providing care under such pressure and discuss three areas of learning from resource-limited settings: (1) integration of palliative medicine into everyday practice, (2) simplification of biomedical management plus multidisciplinary teamwork and (3) effective use of volunteers.

INTRODUCTION

Figurative descriptions of the world turned ‘upside down’, thanks to the novel coronavirus COVID-19, are accurate. Just recently, the idea of much of the world in lockdown and health systems across the world at risk of being overwhelmed would have seemed unthinkable, yet this is the current global reality. The tragedy comes not only from the staggering mortality but also from the possibility that some may die—not because optimal medical care failed—but because stretched (hitherto plentiful) resources may result in the loss of potentially saveable lives.¹ However, even when ventilators and anaesthetists may be in short supply, relief of suffering

need not be rationed. The phrase upside down may point towards dynamic solutions to arm the palliative care (PC) community to better tackle this crisis.

CASE FOR PC IN THE COVID-19 PANDEMIC

At the time of writing, over 375 000 people are reported to have died already with COVID-19,² but this is likely to be an under-representation, particularly under-reporting of non-hospital deaths. Many of those admitted to hospital with severe illness may not have the physical capacity to benefit from intensive care management. However, given over-stretched resources, rationing of intensive therapy may also be required, as in Italy.¹ The resultant cohort of dying patients is complex and heterogeneous. Many needs will mirror those of ‘peace-time’ PC. Indeed, some may already be known to palliative services, their deterioration accelerated by COVID-19. Others may be frail, elderly or have multiple morbidities, without prior PC contact, while others were previously relatively well. Regardless, those who die with COVID-19 are likely to experience similar symptoms: most commonly cough, dyspnoea and fever.³

Comprehensive and accessible clinical guidance has been produced for hospital⁴ and community settings⁵ for management of these symptoms and should be used in conjunction with existing symptom management guidance. The principles of PC assessment and management are unchanged: frequent holistic assessment for symptoms and targeted treatment with non-drug or pharmacological measures.

The clinical evolution of serious COVID-19 and consequent effects on healthcare delivery present additional complex palliative needs. The speed of decline even in the previously healthy may compress the window between emergence of troublesome symptoms



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and death, necessitating more frequent reviews and potentially treatment with higher starting medication doses to achieve comfort.⁴ Unlike those with advanced chronic illness, patients with COVID-19 may be symptomatic, but the ultimate outcome of recovery or death may remain unclear. At this time, clinicians may be reluctant to aggressively manage symptoms for fear of compromising potential recovery. An example is hesitancy to use opioids or benzodiazepines for dyspnoea due to concerns about respiratory depression. Such medications in low doses are beneficial and not usually thought to compromise respiratory function, even in pre-existing lung disease.^{6,7} Therefore, PC should challenge this misunderstanding.

Psychological needs may also be amplified by the speed of decline, along with other structural changes to usual care delivery. Being close to loved ones is important for dying patients,⁸ yet many are dying in hospitals or care homes where visiting is limited or at worst prohibited. Loved ones may be replaced by masked and gowned professionals, themselves advised to minimise time with patients to reduce infection risk. This may increase patients' psychological morbidity. PC is concerned not just with the patient but their families too, who may experience psychological distress and subsequent complicated grief. Relatives' decisions about visiting may be complicated by concerns of contracting COVID-19, or prevented due to their own symptoms, with possible feelings of guilt. After death, social integration is helpful in bereavement,⁹ yet distancing measures risk compounding distress as funeral practices and community contact are severely curtailed.

HARNESSING PC'S INFLUENCE

Cicely Saunders' concept of 'total pain' is as relevant in a time of crisis as when she coined it. An approach to the care of patients, relatives and colleagues that encompasses physical, psychological, social and spiritual concerns is vital. Now more than ever, PC professionals must democratise this approach by not only practising holistic healthcare but also influencing the health system at large to do the same. It has been argued that PC's role at this time 'is to keep the "care" in healthcare, even as systems, patients and providers are under siege'.¹⁰ This may include support for fellow professionals to ensure that the goal of care is not just survival but also reduced suffering. Practically, this may entail psychosocial clinical recommendations, facilitating caregiver conversations and considering spirituality, not just for patients but for all involved, alongside staff support, including facilitating debriefs.

We should also extend beyond fellow healthcare professionals to influencing public discourse. COVID-19 is forcing the global population to face the issue of mortality for themselves and those close to them. Increased advance care planning, including decisions around ceilings of treatment, is being

recommended for frail and elderly people such as those in care homes.¹¹ During the pandemic, both individual communication and public messaging about this sensitive area must balance the need to plan ahead with loved ones while avoiding scaremongering. PC professionals have the communication skills and the experience to sensitively lead this national conversation. A concerted effort is in place to identify and 'shield' those at particular risk of severe COVID-19. Some of this heterogeneous group may want full clinical escalation; others may refuse hospital care. This spectrum merits patient discussion and documentation with both loved ones and health professionals, as would be usual practice, and this cohort is an appropriate group for initial care planning efforts. PC community teams, charities and hospices may be ideally placed to support completion of advance care plans alongside primary care colleagues. This could be a responsive use of the additional funding recently announced for hospices in the UK.¹²

SEARCHING FOR SOLUTIONS: EXPERIENCE FROM RESOURCE-LIMITED SETTINGS (RLS)

The COVID-19 pandemic is unprecedented, but the current situation has strong parallels with the experiences of PC pioneers in RLS. In such areas, care needs outstripping available resources is part of everyday life; potentially avoidable deaths are sadly commonplace. Limitations in availability of palliative medicines and equipment often occur,¹³ necessitating contingency planning and use of alternatives. RLS are also experienced in managing patients dying from infectious conditions like HIV/AIDS and tuberculosis.

Reverse innovation, the practice of adopting lessons from RLS and applying them to high-income contexts, is increasingly recognised within global health and championed by Lord Crisp, who cites multiple potential examples in his book *Turning the World Upside Down - the Search for Global Health in the 21st Century*.¹⁴ Adopting this approach, we now set out some key lessons which could inform a path for PC in the current COVID-19 crisis.

LESSONS FOR THE COVID-19 PANDEMIC: RECOMMENDATIONS FROM RLS

We propose three key areas of response:

1. Integration of PC approaches into everyday practice.
2. Simplification of biomedical management alongside multidisciplinary teamworking.
3. Effective use of volunteers.

We will consider these further and explore possible solutions in each domain.

Integration of PC

The pandemic has led to staff redeployment, many of whom may rarely experience death in their normal workload. The number of patients makes it impossible, and indeed undesirable, for specialist PC services to

be involved with every dying patient. Thus, upskilling staff—particularly those who have been redeployed—is essential. This is a challenge faced by many African countries, as PC is often absent from undergraduate healthcare curricula.¹⁵ The Worldwide Hospice Palliative Care Alliance (WHPCA) toolkit has been used globally to respond, with basic training including holistic exploration of patients' needs, pain assessment and communication skills.^{16 17} Similarly, NHS staff require skills not only in the clinical aspects of caring for a dying patient but also in communication with patients and relatives using simple but effective frameworks such as SPIKES.¹⁸ Training should also cover care of the body and legal arrangements after death, including consideration of the needs of different faith groups, and issues specific to COVID-19 deaths, such as infection control. Many of these topics are in e-Learning for Healthcare modules,¹⁹ and staff should be given paid time to review them.

This could be coupled with a 'link nurse' model, such as that in East Africa (and also some UK hospitals), in which specific staff members are upskilled further in basic PC, and closely linked to their local specialist team for advice and referral where necessary. This has improved outcomes in care, increased PC volumes, changed staff attitudes and relationships and developed new skills and knowledge.²⁰ Such a model could aid rapid identification of need and effective access to specialist support where required during the crisis, particularly in settings such as care homes, which cannot usually quickly access PC support.

Factors discussed previously put patients, families and staff at high risk of psychological distress. Thus, effective integration of chaplaincy and psychological services and a creative approach to the broader needs of the family and community is critical. Webinars and video support groups such as WHPCA 'virtual hubs'²¹ could be considered. Support for family communication could include provision of basic phones or electronic tablets alongside free Wi-Fi. Even when the patient is unable to talk due to breathlessness or deterioration, it can be mutually beneficial for relatives to be able to talk to the patient, and this should be sensitively encouraged and facilitated by staff where possible. Mementoes such as hair cuttings or handprints may comfort and can be packaged and stored before opening to avoid viral transmission.

Healthcare organisations could also consider a physical 'care bundle' for all patients who may be sick enough to die, such as those already implemented in some organisations prior to the outbreak. This could include provision of simple comfort items such as moisturiser, mouth swabs, cough drops and honey/lemon solution, alongside psychosocial support. The latter might include relevant practical information and contact details and access to tailored reading or audio materials that may enhance the patient experience.

Simplified biomedical management and multidisciplinary teams

Healthcare organisations can support staff through regularly updated, locally adapted advice combining excellent national guidelines with local availability. This should provide multiple options for core symptom management, given possible shortages of medications and equipment, such as syringe drivers. These challenges should be anticipated to enable rapid and effective responses when they do arise.

Use of electronic support and decision aids may guide clinicians less familiar with PC. This could include prescriber alerts, such as reminders that with anticipated rapid deterioration, higher starting doses may be needed, as well as electronic prescribing sets for dying patients with COVID-19.

Many RLS use task shifting, in which tasks are moved from highly trained clinicians to those with more limited training. This can be a cost-effective way to provide quality care under appropriate supervision²² and could be applied to redeployed staff such as healthcare assistants, nurse managers and healthcare students. Basic training could enable them to screen for distressing symptoms and perform routine but important tasks, such as repositioning in bed; supporting patient-relative communication or reporting concerns or observations to a more senior colleague. In Brazil, this approach involves symptom screening by community agents of health with limited training,²³ while Hospice Africa Uganda uses task shifting for rapid access to morphine prescribed by nurses and clinical officers with special training.²⁴ Similarly, a patient group directive could enable appropriately trained care home staff (with remote video support from specialists) to administer palliative medications to rapidly declining residents in confirmed institutional COVID-19.

Effective use of volunteers

A systematic review of volunteers in PC reported this was understudied, but they can improve family satisfaction, provide companionship and psychosocial support, and enable links to more formal care.²⁵ Pallium India has long been acknowledged for its extensive volunteer network, backed by the state government and police. This has occurred through the concept that 'chronic and incurable diseases are social problems with medical complications' and community recognition that they may need these services in the future.²⁶ Perhaps for the first time, due to COVID-19, Western society is adopting a similar philosophy. This has led to mobilisation in of 750 000 UK volunteers for the government's NHS Volunteers scheme by 29 March 2020.²⁷ This resource could provide support for time-constrained and overburdened services if screened, trained and managed appropriately.

Creative integration of volunteers, third sector organisations and palliative services could significantly improve care coverage, provide new services

Box 1 Summary of key recommendations

- ⇒ Integrate palliative care into everyday practice.
 - ⇒ Support generalist colleagues to ensure the goal of care is reduction in suffering, not purely survival.
 - ⇒ Consider innovative methods of communicating with and supporting families, such as virtual hubs.
 - ⇒ Consider provision of physical 'care bundles' to support patients and reduce psychological distress of staff.
 - ⇒ Increase understanding and provision of advance care plans, including decisions around ceilings of treatment.
- ⇒ Simplify biomedical management and multidisciplinary team work.
 - ⇒ Ensure easy access to tailored, contemporary clinical guidance and decision aids, including responses to medication and equipment shortages.
 - ⇒ Upskill generalist staff in holistic exploration of needs, symptom assessment and communication skills.
 - ⇒ Consider where task shifting or link nurse models may improve care.
- ⇒ Use volunteers effectively.
 - ⇒ Consider creative integration of volunteers, third sector organisations and palliative services.
 - ⇒ Provide training, guidance and support for psychological support and befriending volunteers.
 - ⇒ Enhance coverage of care and family support; widen the community sense of accountability.

for patients and their families, and perhaps even facilitate patients' preferred place of death. For example, for discharged patients in Jordan, PC nurses provide biweekly phone-call follow-up for advice, medications and family support,²⁸ and these tasks could be further enabled by volunteers. A volunteer model from the Tanzanian Evangelical Lutheran Church uses hospital PC teams to supervise large volunteer cadres, chosen by the community through local government and linked to churches and non-governmental organisations. These groups enhance care coverage and family support, widen community accountability and handle logistical issues enabling the PC team to focus on clinical services.²⁹

Counselling and chaplaincy often already use volunteers, and given their sensitive and challenging remit, volunteers with relevant experience could be recruited from larger volunteer cohorts. For example, St Luke's Hospice in Cape Town has a spiritual care volunteer team, including retired clergy, lay counsellors, psychologists and psychology students.²⁹ These services could be supplemented by less experienced volunteer 'befrienders' who, with minimal training, clear guidelines and formal support, could provide a listening ear to patients, potentially via video link. Many PC and bereavement charities already use volunteers in similar roles and are ideally placed to be commissioned for training and support.

SUMMARY

In the face of potentially stretched resources, relief of suffering embodied by PC must remain 'medicine's moral imperative'.³⁰ Global innovators in PC in RLS have valuable lessons for the UK and other wealthy countries in the current COVID-19 crisis. Our recommendations (box 1) of comprehensive integration of PC, streamlining of clinical management, task shifting and use of volunteers are just a starting point for reverse innovation. To continue this, bilateral learning is essential: as Nigel Crisp argues, 'we are in this together and we will develop together'.¹⁴

The rapid spread of COVID-19 powerfully demonstrates the inextricable global interconnectedness of 21st century societies. Solutions should therefore harness this through learning together to support each other and innovate in the face of adversity. Therefore, we call on the PC community to be outward-looking and support our patients, families and local and global colleagues alike, not just to overcome the COVID-19 crisis, but every day of every week of every year.

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