

ATTACHMENT 6: SPECIFIC GUIDANCE FOR PALLIATIVE CARE

Introduction

The allocation of resources and services during emergency-induced situations of scarcity must be based on a sound ethical framework. Attachment 6 provides specific guidance related to palliative care. Palliative care can be provided in a number of different settings and allows for the provision of comfort and supportive care and services that often complements medical care. Palliative care has a goal of providing the best possible quality of life for people facing the pain and stress of a serious, but not necessarily terminal, medical condition. It can be appropriate for patients of any age and at any stage of an illness and can be provided along with treatments for the medical condition. Palliative care may be provided in many different settings, including in hospitals and other health care facilities, hospice facilities, long-term care and other congregate facilities, and in individual homes. Importantly, since palliative care seeks to reduce pain and suffering, the applicable ethical and practical considerations for allocating palliative care resources and services during times of scarcity may differ from the ethical and practical considerations applied to allocating resources for curative medical treatment.

This guidance document applies the general ethical guidance offered in the *Michigan Guidelines for Implementation of Crisis Standards of Care and Ethical Allocation of Scarce Medical Resource and Services During Emergencies and Disasters* (Guidelines) to the specific context of providing palliative care and addresses in detail some considerations that may arise in different settings. It also offers potential strategies for implementation of the Guidelines in the provision of palliative care and supporting patients seeking this care and their families. This guidance is not envisioned as a formalized series of instructions but rather a set of criteria that can be employed by decision-makers in various circumstances during an emergency or disaster using their best professional discretion. Thus, the criteria offered within these Guidelines are meant to be scalable, adaptable, and functional. Some facilities or providers may not have the capacity to implement all of the suggestions offered in this document. Others will choose to adopt different strategies that are nonetheless consistent with the ethical framework presented in the Guidelines. Some facilities or providers will be obligated to adopt policies and approaches as required by federal or state regulatory requirements. However, all facilities and providers in Michigan that are providing palliative care are strongly encouraged to adapt the approaches and strategies contained in this document, tailored to fit the circumstances of their specific contexts and capacities.

This guidance provides information about both the roles and processes of decision making by facilities and providers of palliative care in planning for and responding to circumstances where contingency or crisis standards of care may apply. It also provides substantive discussion of issues that could arise under emergencies and disasters that impact public health. However, these materials only provide a foundation and a starting point for the development of robust and adaptive policies for addressing crisis standards of care. Extreme or unforeseeable circumstances may challenge the foundations of the framework. In those situations, decision-makers will be expected to use their professional training and prudence to guide allocation decisions. The criteria offered may have to be amended to address unforeseen circumstances and should be constantly reviewed and updated to incorporate new guidance, research, and best practices. This attachment should be used as a tool to assist in the creation of a strong infrastructure and well-designed, ethical policies for addressing resource shortages under crisis standards of care conditions. Additionally, this attachment should be used in conjunction with the other materials applied by the State of Michigan to address emergencies and disasters.

Background

Emergencies and disasters have often led to scarcity of medical resources and services. The history of epidemic outbreaks, natural disasters, and other mass casualty incidents has demonstrated the need to prepare for crisis standards of care across all medical, public health, and long-term care systems. These types of emergencies and disasters could seriously impact the state of Michigan, its health care and public health systems, transportation systems, economy, and social structure. Health care facilities and providers may be faced with higher demands for services, increased employee absenteeism, disruption of supply chains, and increased rates of illness and death among members of the population served by the facilities and providers.

Palliative care is an essential service that must be available and accessible to many people across the state. Resource scarcity may imperil efforts to sustain sufficient access to palliative care in circumstances where an emergency or disaster results in a shortage of resources or a lack of cooperation from the public.

It is of the utmost importance that facilities and providers have the tools necessary to make ethically-appropriate decisions with regard to allocation of scarce medical resources and services, including palliative care resources. The objectives discussed in this attachment will assist decision-makers in protecting the lives and safety of all members of the public.

Applicability of the Guidelines

The Guidelines outline several understandings that define their scope and purpose. The box below restates the factors described in more detail on pages 20-25 of the Guidelines:

1. Emergencies and disasters that impact public health give rise to unique challenges that can lead to, and be exacerbated by, scarcity of medical resources and services.
2. The likely conditions during emergencies—including conditions of medical resource and service scarcity—may be anticipated even in emergency circumstances that arise from sudden, extraordinary, or temporary events.
3. Emergency planners have an ethical duty to plan for and provide guidance related to the ethical allocation of scarce medical resources and services during emergencies or disasters.
4. The Guidelines apply to serious emergencies or disasters that impact public health, not everyday scarcity of medical resources and services. Therefore, the Guidelines envision allocation decisions being made in circumstances where Crisis Standards of Care are anticipated or have been implemented.
5. The Guidelines apply broadly and are meant to inform allocation decisions made by decision-makers at different levels of government and as well as the private and nonprofit sectors.
6. The Guidelines apply to allocation decisions affecting all medical resources and services that may become scarce during an emergency or disaster, including medicines, vaccines, medical equipment, medical devices, personal protective equipment, space, staff, and supportive capacity for health-related functions. However, allocation decisions will differ based on the type of resource and other circumstances.
7. The Guidelines employ ethical principles that take into account both individual health and population health.
8. The Guidelines should be implemented in ways that comply with all relevant laws at the federal, state, and local levels.

In addition to the considerations outlined above, five further understandings are applicable to the potential allocation of scarce medical resource and services in palliative care settings.

1. Scarcity induced by an emergency or disaster that impacts access to palliative care resources and services may occur from direct shortages in the resources needed to provide palliative care, or may be caused due to an increased demand for palliative and comfort care services because other medical care becomes unavailable during an emergency or disaster.
2. The capacity to provide palliative care will be reliant on the functional or operational capacity of health care facilities or providers more broadly. Shortages and diminished capacity in these systems may directly impact the need for, and the capacity to provide, palliative care.
3. Decisions to implement contingency or crisis standards of care do not always occur abruptly and may affect different aspects of the health care system. Some facility operations and dimensions of care may face crisis-level shortages while others are functioning with conventional capacity and efforts to preserve conventional standards in one area may impact capacity in other areas. Demand for and access to palliative and comfort care will fluctuate in relation to these changes.
4. Adaptation of protocols and care processes should involve the minimum modifications necessary to meet the needs of patients needing palliative care under the circumstances.
5. The criteria used to allocate palliative care resources may differ in application from other types of scarce medical resources because the goals of palliative care (e.g., comfort, pain reduction) differ from the goals of curative medical treatment (e.g., reducing morbidity and mortality).

Ethical Considerations for Allocation of Palliative Care

The Guidelines developed for the State of Michigan discuss in detail the principles and methods used to develop the ethical framework and the goals, ethical considerations, and allocation criteria to be used in making scarce resource allocation decisions during crisis standards of care. Several additional ethical considerations applicable to palliative care are highlighted below.

Palliative care promotes significant value in reducing the suffering associated with chronic and acute pain and the experience of advanced illness. In times of scarcity, it is important to consider the value that palliative care uniquely promotes and to ensure that palliative care resources and services remain available to the extent possible.

- Patients benefit significantly from palliative care, including the pursuit of goals that are associated with symptom management rather than curing disease. In particular, palliative care and hospice should not be withheld from patients who are both incapable of medical decision-making as well as unrepresented by a surrogate decision-maker. To do so would be to deny an otherwise appropriate patient a scarce resource based on disability status, which is one of the unacceptable allocation criteria identified in the MDHHS guidelines.
- Reducing pain through palliative care comports with a key ethical value of minimizing suffering. Minimizing suffering is a component of one of the three overarching goals outlined in the Guidelines.
- The use of medically-based comfort care, such as providing pain medication, supports the well-being of people experiencing acute or chronic pain, and is consistent with ethical considerations of beneficence and utility. During circumstances where shortages of pain medication arise due to contingency or crisis standards of care, it may be ethically appropriate to alleviate pain through alternate medical treatments, such as substituting medications, changing dosing, or providing non-prescription medicinal pain relief.
- Palliative sedation is the appropriate and intentional use of medications to produce ongoing, deep unconsciousness upon a terminal patient's (or surrogate's) request due to suffering intractable pain or other distressing clinical symptoms intolerable to the patient when death is expected within hours or days.¹ Palliative sedation is often permissible because it significantly diminishes the disvalue of the patient's suffering.² Resource scarcity does not affect the permissibility of palliative sedation. However, in extreme shortages of the relevant resources, palliative sedation may be withheld.
- Valuable psychosocial support personnel, such as chaplains and social workers, and technology, such as telehealth, associated with palliative care may become scarce. But providers and institutions should recognize the value of this support and provide all reasonable efforts to

¹ This definition is adapted from Karen L. Smith, Terminal Sedation (The University of Tennessee, dissertation, 2011).

² Berlinger, Nancy, Bruce Jennings, and Susan M. Wolf. *The Hastings Center Guidelines for decisions on life-sustaining treatment and care near the end of life: revised and expanded second edition*. Oxford University Press, 2013. p183-184.

provide it. Moreover, adaptive strategies to expand access to non-medical comfort care and service should be considered and planned for.

- Distributive justice requires fair and equitable access, distribution, and opportunity to benefit from scarce resources for all people while pursuing improved outcomes for historically and currently disadvantaged populations. Allocation schemes and criteria that differ substantially between different facilities or providers may result in inconsistent and inequitable outcomes. Cooperation between hospitals, long-term care facilities, hospice facilities, state and local public health departments, Medical Control Authorities, EMS systems, emergency management, hospitals, the State Disaster Medical Advisory Committee, Regional Disaster Medical Advisory Committees, and government officials through the development of consistent allocation guidelines, by contrast, supports distributive justice and equity in access to scarce palliative care resources. The protection of disabled and marginalized individuals by pursuing distributive justice through equitable policies in these circumstances is imperative.

Ethical Duties to Plan, Prepare, and Coordinate

Health care providers in all settings have a duty to plan, prepare, and coordinate with partners to address resource shortages related to palliative care that create contingency or crisis standards of care during emergencies or disasters.

Planning and preparation of health care to respond ethically to situations of resource scarcity underlie both professional and systemic obligations to provide competent and just services to all members of the population. This planning must aim to maximize the provision of palliative care to all people who need it in both medical and non-medical settings.

Preparing health care providers as well as patients and their families for the types of difficult allocation decisions that may arise during crisis standards of care through public engagement and education, supports obligations of honesty and transparency, and adds legitimacy to and accountability for these difficult decisions if they need to be made in the future. Transparency and trust may require acknowledging that the normal level of palliative care and support may not be possible during a situation that requires crisis standards of care. Planning and communication efforts should include input from patients, families, and surrogates. In hospitals, long-term care facilities, and hospice facilities, planning should incorporate guidance from the facility's ombudsman and from applicable federal and state agencies and associations.

Health care facilities and providers have an ethical duty to coordinate with other entities, organizations, and partners that participate in or are likely to be affected by scarcity in palliative care resources and services during emergencies and disasters. Institutional facilities providing palliative care, including hospitals, long-term care facilities, and hospice facilities should coordinate with state and local public health and emergency response infrastructure and regional prehospital entities such as Emergency Medical Services (EMS), Medical Control Authorities (MCA), and regional Health Care Coalitions to understand the capabilities of these organizations during conditions of scarcity. Consistent and coordinated response efforts implementing contingency or crisis standards of care should be pursued in all stages of the planning and implementation process.

Some hospitals, long-term care facilities, and hospice facilities are also subject to federal or state regulations and requirements that may govern their provision of palliative care. Hospitals, long-term care facilities, and hospice facilities that are affiliated with a larger corporate entity have a duty to utilize corporate resources to respond and adapt to resource shortages.

Planning for contingency and crisis scenarios should account for potential situations where hospitals, long-term care facilities, hospice facilities, and home care could pool resources with each other or with other entities or take steps to train and repurpose personnel and/or volunteers to expand capacity and applicable legal orders or mutual aid agreements. Such planning should include a robust consideration of how, where, and what a crisis standard of care would entail and outline expectations for institutions and employees. All facilities must continue to comply with legal requirements during emergencies and disasters.³

³ For more detailed information about legal issues and scarce resource allocation, see Attachment 3.

Implementation

The sections below briefly address the allocation of pain medication.

Allocation of pain medication

The treatment of pain is unique from other medical interventions in important ways. First, determining whether a patient is in pain, and how much pain they are in, requires medical professionals to rely on the patient's subjective report. While there are some objective measures of pain (e.g., increased heart rate), the patient's self-report of pain is definitive. Second, the alleviation of pain is not an all-or-nothing act; it is possible to relieve only some of a patient's pain. In times of scarcity, it is ethically permissible to split pain medication among patients such that some degree of relief is provided to more patients rather than maximal relief of pain to fewer patients. Third, the same *degree* of pain alleviation is not morally equal across patients. On a 10-point pain scale, reducing the pain of a patient at a 10 to a five is better than reducing the pain of a patient at a five to a zero. Therefore, patients in greater pain should be prioritized.

Allocation Criteria:

Ethical criteria for the allocation of pain treatment and management resources differ from ethical criteria applied to other medical intervention due to the functional differences between these resources. For example, the acceptable allocation criteria in the Guidelines include prioritization based on medical prognosis and supporting critical infrastructure (e.g., providing scarce resources to treat or protect health care workers or first responders). Importantly, the treatment of pain in the context of scarcity is different from life-prolonging interventions (e.g., use of ventilators) because the purpose of treating pain is to provide immediate relief that should be administered irrespective of the patient's prognosis (in most cases)⁴ or status as a worker who performs essential functions that support critical infrastructure. Therefore, it is ethically unacceptable to allocate scarce pain medication on the basis of prognosis or status as an essential worker.

Rather, we propose allocating scarce pain medication using a system that prioritizes access to medication to those patients experiencing the most severe pain. All people experiencing pain deserve an equal chance to receive relief from that pain through a system that is responsive to the level of pain they are in. A patient who is offered pain medication has the right to decline, but not direct, the medication they were offered.

With these considerations in mind, the following criteria could be used to allocate pain medication in a time of scarcity:

1. Patients with the highest priority to access pain medication are those patients who need a life-saving procedure that cannot be safely delayed and that will cause severe pain, even if they are not *currently* in severe pain (e.g., they need a quintuple bypass or amputation of a gangrenous foot today). The justification for placing these patients first is that it is better to save a life *and* prevent severe pain than it is to merely intervene on occurrent severe pain. All patients in this

⁴ Prognosis is considered in group one where patients needing treatments that will be very painful and will also extend the patient's life are prioritized. Prognosis is considered in group two where patients who are actively dying are prioritized. For the rest of the patients in the allocation scheme, prognosis is not considered.

category should be allocated sufficient pain medicine to reduce their pain to a moderate level before moving on to the next priority level.

2. The next category of patients in terms of priority are those who are actively dying and in pain. Compassionate care for those at the end of life has a high moral value. For patients who are near the end their lives, the need for pain medication is acute but short term. Palliative sedation is ethically permissible here to ease the pain of patients who are actively dying.
3. The next priority category consists of all remaining patients experiencing pain. Patients in the third tier should be categorized based on two metrics. The first is the level of their pain (e.g., mild 1-3, moderate 4-6, severe 7-10). The second is the patient's tolerance to pain medication, which asks how much pain medication is required to reduce the patient's pain to the next pain level category (e.g., how much medication is required to move a patient in severe pain to moderate pain). Patients in the severe pain category that require a low dose of pain medication to be moved to the moderate pain level category should be prioritized first. Then patients in the severe pain category that require a moderate dose of pain medication to be moved to the next pain level should be treated, and so on. Only when there are no more patients in the severe pain category should patients in the moderate category begin to receive pain medication. Within this framework, the use of a lottery may be ethically appropriate as a tie-breaker between patients with equal priority.

The implementation of this system raises several ethical challenges related to the value of transparency. One important set of considerations involves the appropriate level of transparency that should accompany the implementation of a system for allocating scarce pain medication. Revealing to patients that pain medication is in short supply and will be allocated using a system based on the degree of pain a patient reports could result in patients being untruthful and exaggerating their level of pain to increase their odds of receiving pain medication. This would undermine the goals of the system to create a fair process oriented to alleviating the most severe pain, forcing clinicians into an ethical dilemma between the value of transparency vs beneficence. Informing patients of the shortage of pain medication without disclosing that allocation will be directly impacted by the patient's self-report of pain may serve as an acceptable ethical compromise between transparency and beneficence.

Another consideration that raises ethical challenges related to the value of transparency involves disclosing to patients that they are receiving a reduced dose of pain medication. It is possible that patients who are aware that their usual dosage of pain medication has been reduced due to shortages may experience less relief from the medication as a result of the nocebo effect.⁵ The presence of nocebo effects forces clinicians into an ethical dilemma between transparency and non-maleficence (as the disclosure itself directly causes the resulting increase in harms).⁶ Providing patients with their reduced dosage of pain medication without initially mentioning that the dosage has been reduced, but answering truthfully if directly asked, may serve as an acceptable ethical compromise between transparency and non-maleficence.

⁵ Petersen, Gitte Laue, Nanna Brix Finnerup, Luana Colloca, Martina Amanzio, Donald D. Price, Troels Staehelin Jensen, and Lene Vase. "The magnitude of nocebo effects in pain: a meta-analysis." *Pain* 155, no. 8 (2014): 1426-1434. Benedetti, Fabrizio, Michele Lanotte, Leonardo Lopiano, and Luana Colloca. "When words are painful: unraveling the mechanisms of the nocebo effect." *Neuroscience* 147, no. 2 (2007): 260-271.

⁶ Fortunato, John T., Jason Adam Wasserman, and Daniel Londyn Menkes. "When respecting autonomy is harmful: a clinically useful approach to the nocebo effect." *The American Journal of Bioethics* 17, no. 6 (2017): 36-42.

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Some may plausibly claim that maintaining maximal transparency between health care providers and patients better serves to sustain trust and confidence in the health care setting and with the broader community. In other words, transparency should be fully maintained in the context of a pain medication shortage without any compromise for the sake of beneficence or non-maleficence. On this view, clinicians should disclose the presence of scarcity and allocation schema for pain medication, and disclose the reduced dosage of pain medication to recipients. Such an approach would be ethically defensible despite its reduced ability to uphold the values of beneficence and non-maleficence in the context of pain medication shortage.

Additionally, the implementation of a rubric to ethically allocate scarce pain medication should also consider how the use of alternative pain treatments and therapies may allow for expanded access to other suitable pain treatment options.

The diagram below depicts the levels of priority for allocating pain medication during crisis standards of care. Medication priority goes first to patients in Tier 1 (Box 1), who need a life-saving procedure that cannot be safely delayed and that will cause severe pain, even if they are not *currently* in severe pain. Next priority goes to patients in Tier 2 (Box 2), who are actively dying and in pain. Next, pain medication should be allocated according to assessments of a patient's level of pain and tolerance to pain medication. Patients in the severe pain category that require a low dose of pain medication to be moved to the next pain level category should be prioritized first (Box 3). Then patients in the severe pain category that require a moderate dose of pain medication to be moved to the next pain level should be treated (box 4), and so on, moving up through the numbered boxes on the diagram. Only when there are no more patients in the severe pain category should patients in the moderate category begin being placed in a lottery to receive pain medication.

