Ethical issues in pediatric emergency mass critical care

Armand H. Matheny Antommaria, MD, PhD, FAAP; Tia Powell, MD; Jennifer E. Miller, BS, MBE, PhD; Michael D. Christian, MD, MSc, FRCP(C); for the Task Force for Pediatric Emergency Mass Critical Care

Introduction: As a result of recent events, including natural disasters and pandemics, mass critical care planning has become a priority. In general, planning involves limiting the scope of disasters, increasing the supply of medical resources, and allocating scarce resources. Entities at varying levels have articulated ethical frameworks to inform policy development. In spite of this increased focus, children have received limited attention. Children require special attention because of their unique vulnerabilities and needs.

Methods: In May 2008, the Task Force for Mass Critical Care published guidance on provision of mass critical care to adults. Acknowledging that the critical care needs of children during disasters were unaddressed by this effort, a 17-member Steering Committee, assembled by the Oak Ridge Institute for Science and Education with guidance from members of the American Academy of Pediatrics, convened in April 2009 to determine priority topic areas for pediatric emergency mass critical care recommendations.

Steering Committee members established subgroups by topic area and performed literature reviews of MEDLINE and Ovid databases. Draft documents were subsequently developed and revised based on the feedback from the Task Force. The Pediatric Emergency Mass Critical Care Task Force, composed of 36 experts from diverse public health, medical, and disaster response fields, convened in Atlanta, GA, on March 29–30, 2010. This document reflects expert input from the Task Force in addition to the most current medical literature.

Recent events, including 9/11, hurricanes Katrina and Rita, and the 2009 Influenza A/H1N1 Pandemic, have drawn increased attention to mass critical care. This planning has generally acknowledged, but not explicitly addressed, the needs of children. The Task Force for Mass Critical Care, for example, states that “the area most desperately in need of future study is pediatric triage . . .” (1). A 17-member Steering Committee convened in April 2009 to determine priority topic areas for pediatric emergency mass critical care recommendations. The Committee was assembled by the Oak Ridge Institute for Science and Education with guidance from members of the American Academy of Pediatrics. Steering Committee members established subgroups by topic area, including ethics, and performed literature reviews of MEDLINE and Ovid databases. The Steering Committee produced draft outlines through consensus-based study of the literature and convened October 6–7, 2009, in New York, NY, to review and revise each outline. Eight draft documents were subsequently developed from the revised outlines as well as through searches of MEDLINE updated through March 2010. The Pediatric Emergency Mass Critical Care Task Force, composed of 36 experts from diverse public health, medical, and disaster response fields, convened in Atlanta, GA, on March 29–30, 2010, to provide feedback on each manuscript. The Steering Committee revised each docu-
ment to reflect expert input in addition to the most current medical literature.

The Ethics Subcommittee identified the following priority topic areas: whether there are distinct ethical principles for children, how surge capacity should be allocated among individuals of different ages, what criteria should be used to allocate resources if altered standards of care are necessary, and how these criteria apply to children and adolescents.

Ethical frameworks

Mass critical care planning has occurred at the regional (2), state/provincial (3, 4), national (5–7), and international (8) levels. Many entities frame their recommendations in terms of ethical principles and articulate similar substantive and procedural norms (9, 10).

Many of these guidance documents emphasize the need to protect the public and minimize harm. The lack of planning may produce morbidity and mortality that could otherwise have been prevented, thus creating a fundamental duty to plan. Some policies supplement minimizing harm with maintaining essential social infrastructure. The Ethics Subcommittee of the Advisory Committee of the Director, Centers for Disease Control and Prevention, for example, articulated both the need to minimize serious influenza-associated complications as well as preserve the functioning of society (6). The relative emphasis placed on minimizing harm and on maintaining infrastructure may be based, in part, on the scope of planning scenarios the groups considered. As will be discussed later, whether preserving society's functioning is emphasized has implications for including social roles or narrow social utility as triage criteria.

Existing mass critical care guidance documents enumerate a variety of additional ethical principles. One category of additional principles includes individual liberty, rights, and/or autonomy. The documents argue that individual liberty may sometimes be constrained when it conflicts with society's duty to minimize mortality or clinicians' duty to provide care. The documents also emphasize fairness and equitability as well as proportionality. Proportionality requires that the response be graded to the severity of the disaster (11). Procedural principles include openness, transparency, inclusiveness, public engagement, and accountability. The Committee on Guidance for Establishing Standards of Care for Use in Disaster Situations, for example, argues that “a public engagement process is crucial for drafting ethical policies that reflect the communities' values and deserve its trust” (5). A general limitation of ethical frameworks based on principles is the need to specify the meaning of the principles in concrete cases and to balance the principles when they conflict (12).

Children's unique needs and vulnerabilities

The unique attributes of pediatric mass critical care do not lie at the level of principles but rather in the nature of the subjects. Children have particular needs and vulnerabilities—both physical and psychosocial. For example, their increased body surface area-to-mass ratio and decreased subcutaneous tissue make them more vulnerable to hypothermia. Their decreased herd immunity also makes them more susceptible to many infectious agents. Unique needs and vulnerabilities also exist in the psychosocial domain. Developmentally, children may be unable to describe their symptoms or communicate their wants or needs. They may be limited in their ability to recognize danger, escape, and seek assistance. Their psychological response is also related to their development and attenuated by their caregivers' responses. Children with special healthcare needs may be particularly vulnerable (13).

Many of these needs are met within the family and emphasize the importance of family-centered care (14). While family-centered care is a priority, it may conflict with other goals. Keeping families intact, for example, may conflict with decreasing the spread of infection. Family-centered care also has intrinsic limitations. An inordinate emphasis on the family may erode children's developing autonomy or subordinate their interests to the conflicting interests of other family members or the family itself (15). For example, adolescents should generally be permitted to dissent from proposed interventions.

Mass critical care planning

These unique attributes of children should be considered in all phases of mass critical care planning. Preparation can be divided into three broad components: preventing disasters or limiting their scope, increasing the supply of resources to respond to the effects of mass critical care events, and allocating resources if the demand significantly exceeds the supply.

Prevention. Mitigation in pandemic events, for example, generally involves decreasing transmission through social distancing. Significant ethical issues in prevention and mitigation involve the conflict between protecting public health and constraining personal liberty (6). A general principle is that constraints on liberty must be justified by preventing definite harm or a definite risk of harm to identifiable others (16). While this is an important area of ethical analysis, it includes few issues unique to pediatrics, such as balancing the need for family integrity with the need for social distancing (14).

Surge Capacity. A second consideration is surge planning—the development of additional resources to meet the needs in a disaster. Some surge capacity may be created through modified processes of care, such as medication substitutions or shelf-life extension (17, 18). Such modifications should not result in a decreased standard of care. Surge capacity may also be created although the investment of additional resources. Deciding the appropriate level of investment involves consideration of a variety of factors, including the magnitude and likelihood of various disasters and the benefits and costs of such investments, including the benefit that could have been obtained from an alternative use of the same resource (19). For example, there would be different public health implications of the expenditure of the same amount of resources on current healthcare needs, potential future disasters, and current non-healthcare needs, such as education. A full discussion of this topic is beyond the scope of this article.

In addition to “stuff” and “space,” “staff” are crucial elements in creating surge capacity (17). In addition to providers becoming ill or injured, personnel may not report to work because of concerns about becoming ill and/or infecting family members and friends (11). They may also need to care for their own children, particularly if daycare centers and schools are closed (20). A variety of justifications have been proposed for a duty to treat (21). Previous work has also articulated institutions' and society's reciprocal duty to protect and support healthcare providers by, for example, providing adequate personal protective equipment and possibly disability and life insurance.
While a focus on children and families highlights providers’ conflicting obligations as parents and family members, the Subcommittee concludes that pediatric healthcare providers do not have an additional duty to care relative to those caring for adult patients.

As the article, “Neonatal and pediatric regionalized systems in pediatric emergency mass critical care” indicated, current healthcare resources are distributed differently among various age groups, with more critical care resources being available per capita for adults than children. This is due, in part, to children being generally healthier than adults. Children are, however, likely to be proportionately or even over-represented compared to adults in mass critical care events (22). Distribution of surge capacity should be based on the proportion to those currently or likely to be affected or, if this information is not initially available, on the proportion to those in the general population. There may, however, be practical limitations on creating relatively greater surge capacity for children. The Ethics Subcommittee supports the reallocation of some resources from adults to older children and adolescents (18). Such reallocation represents one of the most significant ethical and practical challenges in planning for pediatric mass critical care.

Triage. While usual standards of care should be maintained as long as feasible, it is possible that the demand for treatment will significantly exceed the supply. In such situations, the failure to plan and alter standards of care could result in excess deaths. To increase the number of survivors, the usual autonomy of both healthcare providers and patients may be constrained. The implementation of crisis or altered standards of care requires a formal declaration at the state or provincial level (5).

General theories of the just allocation of goods include utilitarianism, which emphasizes maximizing net benefit, and egalitarianism, which emphasizes treating people equally. Each of these theories can be specified in terms of a number of secondary principles. Some ethicists argue for a hierarchically ordered combination of both utilitarian and egalitarian principles, beginning with need and benefit, and progressing to conservation of resources, and finally, random allocation (23, 24). These principles may also be supported by other ethical theories or traditions.

While these principles also apply to triage conducted by the emergency medical system (primary triage) and in the emergency department (secondary triage), our discussion will primarily focus on triage conducted within the hospital (tertiary triage). Resources may be triaged when they are initially allocated or they may be reallocated at future points in time. While patients are continually reevaluated to determine whether they have sufficiently improved such that they no longer require critical care, they could also be reevaluated at fixed periods of time or if their clinical status significantly deteriorates. Critical care resources might then be withdrawn and reallocated to other patients. While most ethicists contend that there is no morally relevant distinction between withholding and withdrawing treatment (12), reallocating resources would represent a significant change in the standard of care. While supporting periodic reevaluation, the Subcommittee also recommends wider discussion of this controversial issue.

We believe that the allocation or reallocation of scarce resources should be based on several fundamental principles. Critical care resources should be limited to patients who need them—those who will die or be seriously disabled without such treatment. Resources should also be focused on those who will benefit from them. To the extent it is possible to identify those who will die even with treatment, these individuals should be excluded. They, nonetheless, should be provided with appropriate palliative care (1). It is also possible that different individuals will require different amounts of resources to survive. If several children could be saved with the resources used to treat one, the Subcommittee believes it is ethically appropriate to favor several over one. For example, extracorporeal membrane oxygenation may require a significantly higher staff-to-patient ratio (17) and might be forgone during mass critical care. Finally, if there remain more eligible patients than resources and providers cannot draw ethically relevant distinctions between them, treatment should be allocated based on queuing or lottery.

Prediction methods. Predictions of benefit and resource utilization may be objective or subjective. Objective estimates are based on statistical analysis of the relationship between a finite number of reproducible variables and the relevant outcome. Subjective estimates, such as expert opinion and clinical judgment, are based on the knowledge and experience of the individual or individuals making the estimate (25). Since objective scoring systems may incorporate subjective data and vice versa, this distinction is only relative.

Scoring systems’ accuracy can be described in terms of discrimination and calibration. Discrimination is the ability of the tool to separate patients into groups, and calibration is the relationship between the estimates and actual outcomes (25, 26). Some studies suggest that both objective and subjective estimates have similar abilities to discriminate but that subjective measures tend to overestimate mortality (27, 28). Given the limited accuracy of existing systems, some individuals who would benefit from critical care will be erroneously triaged not to receive it. This shortcoming is, however, generally outweighed by the ability to exclude patients who are unlikely to benefit from treatment. Accuracy may be improved by focusing on the extremes or on broad categories (27, 29).

While subjective and objective predictors may have similar abilities to discriminate, they have other relevant benefits and detriments. There may be significant variation between clinicians in their subjective estimates, and subjective estimates may be influenced by unconscious or even intentional bias. While education and procedural safeguards may be used to decrease bias, most commentators, including this Subcommittee, generally favor objective systems. Objective systems vary in terms of the clinical conditions or populations they are validated for, the number and complexity of the variables they require, and how easy they are to use (29). Scoring systems developed on medical or postsurgical patients, for example, may be inapplicable to trauma patients. The Sequential Organ Failure Assessment score utilized by many adult triage protocols (1, 3) has unfortunately not been validated for general pediatric use. Available pediatric scoring systems, such as the Pediatric Risk of Mortality and the Pediatric Index of Mortality, have limitations, including inapplicability at the time of admission to the intensive care unit, reliance on laboratory testing, and complex formulas (18). Given the lack of a simple, validated pediatric scoring system, this Subcommittee concurs with the Treatment and Triage Subcommittee (18) and hesitantly recommends the use of expert opinion within systems to mini-
mize bias in its application. The Subcommittee emphasizes the need for ongoing research, potentially during the mass critical care event itself, to develop appropriate pediatric scoring systems.

Queuing and lottery. If a scoring system cannot distinguish between potential candidates and resources remain scarce, one may need to rely on other methods of allocation, such as first come, first served or queuing and lottery.

Queuing has both advantages and disadvantages. A waiting list is easy to administer and knowing one’s place on the list can provide comfort to patients and families. Queuing, however, is not truly random and may be influenced by ethically irrelevant considerations. Patients with better information, transportation, or connections may enter the queue earlier or progress more rapidly. A system of queuing may further disadvantage the vulnerable (6, 24).

Similarly, lotteries have their own benefits and detriments. Lotteries assure equality of opportunity and minimize judgments about individuals’ relative value. While lotteries may diminish the influence of knowledge, resources, or social relationships, it may be difficult to define the rules for administering lotteries, such as who is eligible, especially during mass critical care events. In addition, individuals may perceive leaving the decision to chance as an abdication of moral responsibility (24). This may create additional hostility in an already tense situation.

The choice between waiting lists and lotteries is based on ethical, psychological, and practical considerations about which there is reasonable disagreement. The Subcommittee did not reach consensus on which is preferable, nor do we believe a societal consensus exists on this issue. The Subcommittee calls for public engagement to address this issue as well as others where agreement is lacking.

Narrow social utility. Members of the Subcommittee concur with previous guidance documents that allocation based on various social factors is unethical. These factors include gender, race, religion, ethnicity, sexual orientation, and ability to pay (6).

Some authors, however, support allocation according to narrow social utility—the individual’s role in supporting essential social infrastructure (in contrast, broad social utility is an individual’s general social worth). Others object that narrow social utility intrinsically discriminates against children, who are not employed, and underestimates children’s socially important role as symbols of hope and the future. Even if one accepts a role for narrow social utility, a number of issues exist in its application. No consensus exists on which roles are essential and how many individuals are required to fulfill each role (30). Different interventions may also have different effects on individuals’ ability to remain at or return to work. While immunizations may be effective in allowing healthcare providers to remain at work during a pandemic, a healthcare provider requiring intensive care is unlikely to recuperate quickly enough to return to work during the height of the pandemic (4). These practical issues, however, are not specific to pediatrics.

Age. Some individuals have recommended age as an allocation criterion. These proposals take a variety of forms. To the extent that age is a predictor of benefit and/or resource utilization, it is insufficiently sensitive or specific. Others have proposed limiting resources to those who have exceeded a natural life expectancy (31).

More immediately relevant to pediatrics is the “complete lives system,” which prioritizes adolescents and young adults. Proponents of the complete lives system, citing Ronald Dworkin and empirical surveys, assert that the death of an adolescent is a greater loss than the death of a toddler or an infant. While empirical research alone cannot resolve ethical issues, we find that the claims of Persad et al (32) are not supported by the studies they cite. Richardson (33), for example, does not address the loss of younger compared to older children, but instead discusses individuals’ willingness to have government override public opinion. Tsuchiya et al (34) report that the literature has generally not examined the relative value given to infants and children compared to adolescents and adults and, when it has, the results are inconsistent. Their own study of the issue has limited generalizability. In contrast, recent polling on behalf of the American Academy of Pediatrics demonstrates support for the prioritization of children over adults (35).

In terms of their theoretical argument, Persad et al (32) focus on personal and societal investment in individuals and the individual’s ability to form and value long-term plans. Apart from their validity as discriminating factors, it is not clear that these considerations necessarily correspond with age. Individuals may receive different levels of investment and the return on the investment may occur at substantially different ages. For example, an infant born after several unsuccessful cycles of in vitro fertilization may have already received a substantial investment. Furthermore, while both an Olympic gymnast and a pediatric neurosurgeon are the recipients of substantial investments, the gymnast’s return may occur in adolescence and the neurosurgeon’s in middle age. The Subcommittee believes the complete lives system is an inappropriate basis for allocating scarce resources. Other age-based criteria require further evaluation.

Implementation. A number of issues should be considered in implementing triage plans. Individuals who are not provided curative treatment must be provided palliative care (1). Consideration of the boundary between palliation and euthanasia, and whether euthanasia might be justified in exceptional circumstances, is beyond the scope of the Subcommittee’s work. Currently, patient care decisions are made jointly by patients and their healthcare providers. During mass casualty events requiring altered standards of care, triage decisions should be made by officers or teams not involved in direct patient care (1). This role sequestration minimizes the conflict between providers’ duty to advocate for their patients and society’s obligation to maximize survival. Triage officers and teams also have greater situational awareness than those providing direct patient care. There is controversy over whether individual triage decisions should be subject to review and, if so, on what grounds (1,36). Aggregate outcomes should, nonetheless, be monitored during the event and modifications in the process made as appropriate. Clinicians may have difficulty withholding and withdrawing treatment. Psychological and spiritual support should be provided to families and clinicians when treatment is withdrawn in the context of a disaster. Finally, an appropriate legal framework is needed, including support for clinicians who follow altered standards of care in good faith (5,37).

CONCLUSION

This article has attempted to identify areas of consensus and disagreement among experts. There is, for example, agreement about allocation based on need, benefit, and conservation of re-
sources, but no consensus regarding the relative benefits and detriments of queuing and lottery. Additional work is needed to engage the public in this discussion (5). Some public engagement has already been done in pandemic planning (38, 39). Methodologic issues include number and selection of participants, identification and presentation of information, method of deliberation, and utilization of outcomes (40).

Recommendations

1) Surge capacity for children should be based on their proportion of the population or, preferably, in proportion to those currently or likely to be affected by the mass critical care event rather than in proportion to existing infrastructure.

2) If altered standards of care become necessary, resources should be allocated on the basis of medical need, medical benefit, and the conservation of resources. Given the absence of a simple, validated, objective pediatric scoring system, the Subcommittee hesitantly recommends the use of expert opinion. Neither waiting lists nor lotteries are clearly preferable to the other. Resources should not be allocated based on the complete lives system or on gender, race, religion, ethnicity, sexual orientation, or ability to pay.

3) Further work is needed to develop practical, validated pediatric scoring systems that accurately predict mortality and resource utilization.

4) Public engagement in this discussion is essential.

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REFERENCES


APPENDIX

Task force members in alphabetical order

Terry Adirim, MD, MPH, Department of Homeland Security, Washington, DC; Michael Anderson, MD, FAAP, Rainbow Babies and Children’s Hospital, Cleveland, OH (Steering Committee); Andrew Argent, MD, University of Cape Town Red Cross War Memorial Children’s Hospital, Cape Town, South Africa; Armand H. Antoninmaria, MD, PhD, University of Utah School of Medicine, Salt Lake City, UT; Carl Baum, MD, Yale-New Haven Children’s Hospital, Woodbridge, CT; Nancy Blake, RN, MN, American Association of Critical Care Nurses, Los Angeles, CA; Desmond Bohn, MB, The Hospital for Sick Children, Toronto, Ontario, Canada (Steering Committee); Dana Brainer, MD, Oregon Health and Science University, Portland, OR; Debbie Brinker, RN, MSN, American Association of Critical Care Nurses, Spokane, WA (Steering Committee); James Broselow, MD, University of Florida, Hickory, NC; Frederick Burkle, MD, MPH, DTM, FAAP, FACEP, Harvard School of Public Health, Cambridge, MA (Steering Committee); Jeffrey Burns, MD, MPH, Children’s Hospital Boston, Boston, MA (Steering Committee); Michael D. Christian, MD, FRCP(C), University of Toronto, Toronto, Ontario, Canada (Steering Committee); Michael D. Christian, MD, FRCP(C), University of Toronto, Toronto, Ontario, Canada (Steering Committee); Sarita Chung, MD, Children’s Hospital Boston, Boston, MA; Edward E. Conway Jr, MD, MS, FAAP, FCCM, Beth Israel Medical Center, New York, NY (Steering Committee); Arthur Cooper, MD, MS, FACS, FAAP, FCCM, FAHA, Columbia University Medical Center, New York, NY; Steven Donn, MD, FAAP, CS Mott Children’s Hospital, Ann Arbor, MI (Steering Committee); Andrew L. Garrett, MD, MPH, Department of Health and Human Services, Washington, DC; Marianne Gausche-Hill, MD, FACEP, FAAP, Harbor-UCLA Medical Center, Torrance, CA (Steering Committee); James Geiling, MD, VA Medical Center, White River Junction, VT; Robert Gougelet, MD, New England Center for Emergency Preparedness, Lebanon, NH; Robert K. Kanter, MD, SUNY Upstate Medical University, Syracuse, NY (Steering Committee); Niranjana Kissoon, MD, FRCP(C), The British Columbia Children’s Hospital, Vancouver, BC (Steering Committee, Chair); Steven E. Krug, MD, FAAP, Northwestern University’s Feinberg School of Medicine, Chicago, IL (Steering Committee); Maj. Downing Lu, MD, MPH, FAAP, Walter Reed Army Medical Center, Washington, DC; Robert Luten, MD, University of Florida, Jacksonville, FL; Lt Col (USAFR) Michael T. Meyer, MD, FAAP, Wilford Hall Medical Center, Lackland AFB and Medical College of Wisconsin, Milwaukee, WI; Jennifer E. Miller, MS, Bioethics International, New York, NY (Steering Committee); W. Bradley Poss, MD, University of Utah, Salt Lake City, UT; Tia Powell, MD; Montefiore-Einstein Center for Bioethics and Einstein-Carodoz Masters of Science in Bioethics, Montefiore Medical Center and Albert Einstein College of Medicine, Bronx, NY; Dave Siegel, MD, National Institutes of Health, Bethesda, MD; Paul Sirbaugh, DO, Texas Children’s Hospital, Houston, TX; Ken Tegtmeyer, MD, FAAP, FCCM, Cincinnati Children’s Hospital Medical Center, Cincinnati, OH (Steering Committee); Philip Toltzis, MD, Rainbow Babies and Children’s Hospital, Cleveland, OH (Steering Committee); Donald D. Vernon, MD, University of Utah, Salt Lake City, UT (Steering Committee); Jeffrey S. Upperman, MD, Children’s Hospital Los Angeles, Los Angeles, CA (Steering Committee).