

SPECIAL FOCUS

Ethical Issues Raised in Addressing the Needs of People With Serious Mental Disorders in Complex Emergencies

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ABSTRACT

Recent manmade and natural disasters highlight weaknesses in the public health systems designed to protect populations from harm and minimize disruption of the social and built environments. Emergency planning and response efforts have, as a result, focused largely on ensuring populations' physical well-being during and after a disaster. Many public health authorities, including the World Health Organization, have recognized the importance of addressing both mental and physical health concerns in emergency plans. Individuals with mental disorders represent a notable proportion of the overall population, and anticipating their needs is critical to comprehensive emergency planning and response efforts. Because people with serious mental disorders historically have been stigmatized, and many individuals with mental disorders may be unable to care for themselves, ethical guidance may be of assistance to those engaged in emergency planning and response. This article considers several broad categories of ethical issues that arise during emergencies for people with serious mental disorders and offers recommendations for ways in which emergency planners and other stakeholders can begin to address these ethical challenges.

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Recent disasters have highlighted weaknesses in the public health systems intended to protect populations from harm and minimize secondary effects of disruption to the social and built environments.¹⁻³ Although emergency planning and response efforts often focus on securing populations' physical well-being during and after disasters, the World Health Organization (WHO), among other public health authorities, recommends including mental and physical health as components of emergency preparedness.⁴

Public health and relief officials have long recognized the need to identify and respond to the acute emotional distress produced by disasters, but they have not focused on the needs of people with preexisting serious mental disorders. People with mental disorders represent a notable proportion of the population.⁵ They are susceptible to deterioration of their health status during emergencies, with possibly long-term or irreversible consequences.^{6,7} This may be the case especially for those among marginalized populations with mental disorders who experience discontinuities in their care and disruptions of tenuous social and economic supports that are essential to their stability. Because people with mental disorders historically have been stigmatized and may be unable to care for themselves, ethical guidance can be particularly informative to those engaged in emergency planning efforts.

Mental disorders are grouped into several categories. Some are relatively mild disorders affecting functioning, but are amenable to brief treatments or some-

times resolvable on their own. Others are more severe and are marked by changes in mood, perception, cognition, and behavior. Left untreated, these disorders severely impair a person's ability to function independently within families, communities, schools, or workplaces.⁸ Fortunately, for most mental disorders, treatment can restore functionality in most or all areas of life.⁹ Emergency planning should help individuals with these disorders maintain needed levels of treatment and support. Alternatively, emergency planning should, at minimum, strive to prevent harm from which the individual cannot recover once the emergency ends.

In this article, we consider equity issues that arise during emergency planning for people with serious mental disorders. We discuss 3 broad categories of ethical issues that may appear during emergencies: attempts to minimize the harm that may occur because of lapses in treatment for mental disorders, ethical issues that arise when attempting to protect people with mental disorders from experiencing stigma during emergencies, and ways in which the autonomy of individuals with mental disorders can be respected amidst challenges that arise during emergencies. We offer recommendations for ways in which emergency planners and other stakeholders can begin to address these ethical challenges. These recommendations are intended to serve as a starting point for those seeking to improve preparedness efforts for individuals with mental disorders.

EQUITY IN EMERGENCY PLANNING FOR PEOPLE WITH MENTAL DISORDERS

Emergency preparedness efforts focused on the health needs of people with mental disorders are lacking compared with planning for those with other health needs. This represents a serious oversight on the part of emergency planners. Because of associated cognitive or emotional problems, some individuals with mental disorders may have limited capacity to advocate or care for themselves.¹⁰ In addition, individuals with serious mental disorders may relapse because of interruptions in social and medical support.¹¹

The vulnerability of people with mental disorders is often compounded by the inability of the public, representatives of civil institutions, and general medical personnel to recognize or diagnose mental disorders. People who exhibit symptoms of mental disorders often are treated punitively until the nature of their condition is understood.¹² They may be perceived as being less deserving of curative or palliative resources than individuals with other health problems,^{13,14} and this perception has contributed to a long history of abuse and neglect.¹⁵

Individuals with mental disorders form a substantial subset of the population. The lifetime prevalence rates for diagnosis-level mental disorders are approximately 10%. Most mental disorders are chronic, with waxing and waning severity across the lifespan.^{16,17} Although people with mental disorders are not more deserving of resources than are others, they are less likely to receive resources during emergencies unless deliberate plans are made for their care.^{18,19} Issues have included presumptions that these individuals are incapable of providing consent for treatment; that they are dangerous to others; and that they are an embarrassment, handicap, or risk to their families. Despite significant reforms to the US mental health care system, mental disorders are treated under a lesser standard of care compared with physical disorders.²⁰ Mental health expenditures lag behind expenditures for physical disorders.⁸ People with mental disorders are sometimes presumed to be less worthy of care. Their treatment may be considered less scientific and more arbitrary than treatments for physical impairments. Until the recent passage of federal mental health parity laws,^{21,22} individuals and families bore a greater proportion of the burden for mental health services than for somatic health services.²³

Distinguishing among mental disorders, mental suffering, and mental health is important. Although these concepts often are placed on a single continuum and all, presumably, are within mental health workers' scope of practice, they raise independent issues.²⁴ During complex emergencies, many individuals experience disturbance or disruption in their sense of mental health. They encounter limits to feelings of agency, their ability to relate to others, their feelings of self-acceptance, and even their sense of purpose.²⁴ Similarly, some individuals, during emergencies, experience mental suffering, including feelings of grief and loss, demoralization, and, at times, symptoms of anxiety and thoughts that transiently take on the characteristics of a mental disorder.²⁵ Some of these individuals may go on to develop mental disorders, most notably posttraumatic conditions. Both

of these groups are worthy of care, and much has been written about ways to prevent or palliate their suffering during emergencies.²⁶ Individuals with preexisting mental disorders, however, face unique challenges during emergencies caused by factors that risk causing deterioration in their conditions.²⁷ Nearly every model of mental disorder proposes that individuals' emotions and behaviors are products of interactions between innate characteristics and the social and physical environment. Even disorders that are believed to be caused largely by heritable, infectious, or toxic brain dysfunction—including schizophrenia, bipolar disorder, and dementia—can vary in manifestation because of environmental influences.²⁸ This interaction between brain and environment exists for everyone; however, individuals with mental disorders are more dependent on a supportive environment to maintain normal function.

A second concern for individuals with preexisting mental disorders is that deterioration of their condition during emergencies may involve prolonged recovery or may even be irreversible.^{11,29} Suicide rates among people with serious mental disorders exceed those in the general population.³⁰ With some mental disorders (notably schizophrenia and bipolar mania), repeated relapses diminish the chances of full remission and increase the likelihood of future relapse, even with continued treatment.^{31,32} Individuals from marginalized populations (eg, undocumented immigrants receiving mental health care from safety net sites) may be especially vulnerable because in emergencies they are at a higher risk than those in non-marginalized populations to become homeless and separated from social supports or to encounter language or legal barriers to receiving alternative clinical services.³³

MINIMIZING HARM FROM LAPSES IN MENTAL HEALTH CARE

Many individuals with mental disorders can function normally with ongoing intervention.³⁴ Consistent treatment also may be required to prevent irreversible loss of function or death and possible harm to others. As with many other chronic medical conditions, including renal dialysis and some cancer and hematologic treatments, the treatment of mental disorders requires long-term contact with providers.¹⁰

Competent Personnel Consistent Access

Even the wealthiest countries lack sufficient mental health personnel and they are poorly distributed geographically.³⁵ Under nonemergency circumstances, individuals often must travel great distances to reach good-quality mental health care services.³⁶ Under emergency circumstances, the ability to travel to reach available care typically is disrupted. For people with mental health needs, the inability to travel may prove especially problematic, given both the poor distribution of services and the importance of face-to-face contact.³⁷

One means of minimizing harm from disruption of services during emergencies is to integrate some mental health services into general medical facilities. Integrating such services may result in more

even resource distribution, provide greater access across communities, and allow mental health services to become routine within emergency planning. In addition, the families and generalist providers of services to individuals with mental disorders and the individuals themselves may be helped via electronic means if communication channels remain open during emergencies. Several recent studies have demonstrated, for example, the effectiveness of “telemedicine” for mental health service delivery, including telephone therapy, telepsychiatry, and remote consultation.^{38,39}

Competence Among Mental Health Practitioners

The supply of mental health practitioners is limited in routine care contexts. In emergencies, patient loads may increase, mental health practitioners may be incapacitated, and other practitioners may lack training to effectively manage chronic mental health problems. It is not surprising that mental health planning, preparedness, and response efforts rely upon nonmedical personnel (eg, clergy, caregivers) to provide some mental health services.^{40,41} For individuals whose mental health is impaired temporarily because of the emergency, access to these personnel may help. For people with chronic, serious mental disorders, however, access to trained mental health providers is essential. Even presuming that these personnel are available, their delivery of services is likely to be directly affected by the emergency. The Institute of Medicine (IOM) has provided guidance about how to implement “crisis standards of care” in emergencies.⁴² The IOM recommends that mental health providers receive training in transitioning patients to different medication regimens or managing behavioral conditions without access to traditional treatments.

Competence Among Nonmental Health Practitioners

Emergency responses that deliver integrated health services may result in individuals with mental disorders receiving care from medical generalists (eg, nonpsychiatrist physicians, nurses, physician assistants, paramedics). Mental health expertise among generalists is low, particularly for the treatment of persistent, chronic mental illnesses.⁴³ General training programs have little mental health content. Thus, although a generalist physician may have some knowledge of several medical subspecialties, she or he may have relatively little mental health expertise beyond identifying and treating mild depression.⁴⁴ WHO⁴⁵ and the American Academy of Pediatrics⁴⁶ have launched programs to improve systematically generalists’ mental health skills, typically during nonemergency times. Additional mental health preparedness training or enhanced treatment handbooks may help generalists to provide some mental health services in emergencies.

One challenging issue in this context is the level of competency expected of generalist providers. How much precious preemergency training time can be devoted to mental health issues? Psychotherapy skills take years to learn and lifetimes to perfect, but core communication skills are more easily acquired and are useful across a range of medical issues.⁴⁷ It is possible to assemble a limited formulary of easily administered medications for a wide range of mental health problems^{48,49} and develop a core set of emergency mental health skills that could

be incorporated into preemergency training. Most important, generalist providers should know how to recognize mental illness so that they are able to provide appropriate responses (eg, suicidal thought is not perceived as “normal” in the context of emergencies; aggressive or irrational behavior is not perceived as characterologic and treated punitively). Closely related is the use of restraint and sedation for individuals appearing to be aggressive or disoriented. These devices once were common tools in the care of people with severe mental illness—with significant morbidity and mortality for patients and staff.¹⁵ Alternate approaches have reduced the need for these forms of “care,” even as acuity in inpatient units has increased. Alternatives, however, require staff who are well-trained.⁵⁰ Efforts undertaken through emergency planning initiatives to help define key symptoms, management strategies, and basic “dos and don’ts” of serious mental health disorder management could produce enormous benefits within and beyond disaster contexts.

Problems in Patient–Provider Communication

Care for mental health problems often depends upon patients’ ability to communicate. All patient–provider interaction depends, to some extent, on spoken (or written) communication, but mental health problems often cannot be detected unless someone can communicate thoughts or experiences. Emergency systems must overcome language barriers, because some of the most vulnerable individuals come from minority-language communities.

Continuous Supply of Medication

Many individuals with mental disorders depend upon medication for stability; their conditions may become dysfunctional in days or weeks if treatment is interrupted.⁵¹ The medications used by some individuals (eg, children using stimulants to treat attention-deficit/hyperactivity disorder and adults using benzodiazepines to treat anxiety) are regulated as controlled substances under federal law, which may further impede their prescription or distribution in emergencies. It is critical to ensure a continuous supply of medication during and after emergencies.

Because medication shortages are likely to arise, federal, state, and local governments should consider stockpiling medications for mental health disorders in accordance with a crisis standard of care. Although no consensus exists regarding which medications should be stockpiled, WHO’s model list of essential medicines offers a reasonable starting point.⁴⁹ This list could be evaluated against an analysis of “switching” studies, which identify the ways in which individuals may transition to stockpiled medications if preferred medications are unavailable. Studies suggest that medications of the same class and indication are equivalent at a population level^{52,53}; however, adverse effects and effectiveness can vary tremendously among individuals.⁵⁴ Changing from 1 medication to another presents clear risks.

Minimizing these risks may be possible by providing individuals with chronic mental health problems a small stockpile of their usual medication for safekeeping at home. Assuming that

individuals are not displaced, this may allow for continuity of medication for periods of ≥ 1 month. Federal controlled substances laws could include an exception for emergencies that would allow certain psychotropic drug prescriptions to authorize a supply beyond 30 days.

Protection From Stigma

The potentially stigmatizing nature of serious mental illness is protected through privacy laws and policies about the recording and sharing of mental health information.⁸ These laws and policies, however, recognize that acquisition, use, and disclosure of identifiable mental health data among providers are vital to the care of individuals with mental disorders, who may, at times, be unable or unwilling to tell providers about their past conditions and treatment.

Continuity of mental health care typically reduces the need for transfer of records or information among clinicians, and record security can be maintained through password-protected electronic systems and locked paper files. In major emergencies, however, these protections are often disrupted, leading to increased opportunities for confidentiality breaches and stigmatization of people with mental disorders, despite legal assurances that equal care be provided. Lack of continuity also multiplies the number of times that information is transferred and the number of people who know the individual's condition, thus increasing the chances of inadvertent disclosure.

Existing privacy laws and practices may disrupt the flow of identifiable mental health data to the appropriate personnel.⁵⁵ At balance are the risks of harm to patients from breaches of privacy vs the need for medical personnel to access data to provide adequate treatment. During declared emergencies, provisions of health information privacy laws, such as the Health Insurance Portability and Accountability Act Privacy Rule, may be temporarily suspended to facilitate information sharing, which may contribute to inappropriate access to or storage of mental health records.⁵⁵

Care in integrated medical/mental health settings offers some protection from privacy breaches and stigma by avoiding an obvious "mental health" venue and allowing direct communication among medical and mental health providers. Many emergency medical facilities lack adequate privacy practices for preserving the confidentiality of oral communications, electronic communications, or emergency correspondence, however. Greater attention paid to the privacy of mental health data throughout declared emergencies may enhance protections of those with mental disorders from stigmatization.⁵⁶ Preparedness planners also may develop methods to alert general medical providers to the need to maintain privacy, even in disaster settings.

Respect for People and Their Choices

The demands posed by complex emergencies may result in placing limitations on the autonomy of nearly all individuals through requirements for curfews, limitations on access to public gathering places, and limited privacy protections. It is incumbent on pub-

lic health and other government authorities to anticipate such alterations of usual practice, determine how to minimize their effect, be transparent with the public about why such changes are being implemented, and reassure the public that usual practice will return as soon as possible. The negative impact of these changes may be heightened for those with mental disorders. For example, it is well demonstrated that anxiety can reduce the ability to perceive one's environment accurately, search for relevant memories, and juggle options involved in complex decision making.⁵⁷ These limitations may be exacerbated in individuals with mental disorders. Decision making time may be slowed because of reduced reaction or processing time, greater distractibility, the presence of associated cognitive problems, or adverse effects from medications.⁵⁸ Observers may be unaware that individuals are experiencing cognitive problems and perceive a lack of decision-making ability as a sign of opposition or incapacity.

In nonemergency contexts, individuals with mental disorders may exhibit behaviors or mood states that seem threatening; this may lead to their deprivation of choice or freedom.⁵⁹ During emergencies, the impulse to deprive anyone exhibiting potentially threatening behavior of their freedom may be heightened. Even when it is prudent to implement such an approach, principles of the "least restrictive intervention" are components of multiple ethical guidelines and have become a standard of care that has been shown to lead to the most rapid return to functionality.

Another threat to choice is that individuals with mental disorders who have relapsed and who cannot make a choice about their treatment may be separated from designated proxy decision makers, psychiatric advance directives, or medical records that indicate their preferred and most effective form of treatment. This situation can be mitigated or avoided by using measures similar to those used to keep families together during complex emergencies,⁶⁰ and perhaps by encouraging individuals with mental disorders to carry with them contact and basic treatment information at all times.

Should an emergency arise, planning would, it is hoped, have created a replacement for established proxy decision mechanisms to guide involuntary treatment. Because of past abuses of involuntary treatment, elaborate mechanisms now represent the best interests of individuals who may require confinement or medication or to protect them from perceived self-injurious behavior.⁶¹ These mechanisms include guidelines and decision makers for compelling emergency evaluations, the need for more than a single provider's decision to confine a patient involuntarily, and guidelines for timely review of decisions and for supervision of ongoing care.^{62,63} These procedural mechanisms may be difficult to maintain in emergencies. For example, the judicial system may not function completely during an emergency. Alternative mechanisms to provide due process are needed, including technology to permit judicial officers to participate in hearings remotely, as well as limiting terms of involuntary confinement or treatment.

Recommendations

Individuals with mental disorders face unique challenges during and after emergencies. Because they are a vulnerable group, it is important to consider ethical issues that will arise as part of their care and treatment. The recommendations below, which are grouped into categories by stakeholder, may assist emergency planners and others in addressing these ethical challenges. These recommendations are intended to be viewed as a whole, because many of them are relevant to multiple stakeholders.

Federal Regulators

1. “One month ahead” medication supplies should be part of the usual care provided to individuals who require long-term medication to maintain stability. This would, however, require changes in federal laws that regulate prescribing and dispensing of psychotropic medications and other controlled substances. Federal regulators could establish a standard formulary of medications used to treat mental health issues that will be stockpiled for emergencies. Using this formulary, mental health providers could identify “emergency” medication substitutes for patients, in the events that the usual medications are unavailable during emergencies. Changes to prescription drug insurance practices, which sometimes reimburse for a maximum 30-day supply, also may be needed.

2. Emergency medication stockpiles should include a broadly applicable mental health formulary, perhaps modeled on WHO’s model list of essential medicines. Stockpiles should be accompanied by guidelines that address ways in which to rapidly and safely transition patients to medications available in essential medication kits.

3. If the judicial system is disrupted, alternative procedures for providing notice, a hearing, and counsel—the minimum standards for due process—should be developed. This may include using video and/or audio systems to permit judges and lawyers from outside the affected area to participate. Involuntary treatment or confinement under these circumstances should be limited to the time needed to provide more usual procedural safeguards.

Professional Associations

4. Organizations of mental health providers (eg, social workers, psychologists, psychiatrists) should develop training materials and methods that help their members support patients during complex emergencies. The American Psychiatric Association,⁶⁴ the National Association of Social Workers,⁶⁵ the American Academy of Child and Adolescent Psychiatry,⁶⁶ and the American Psychological Association⁶⁷ have developed materials that begin to address these needs.

5. Minimal competencies for mental health first response should be developed for general health care providers. The IOM and others have proposed generating specific guidance on the delivery of mental health services in declared emergencies that is consistent with a crisis standard of care. Training programs being developed for low-resource countries that focus on practical issues regarding diagnosis and management may provide useful mod-

els. In addition, some US practitioners have developed materials to aid mental health workers during disasters.^{41,68} Little is known about the effectiveness of these training materials, but there are examples of police training materials that discuss effective ways of addressing potentially dangerous behaviors that are likely caused by mental illness.⁶⁹ It may be necessary to develop an alternative treatment philosophy of brief interventions that are applicable to a range of conditions rather than asking generalists to take on psychiatric diagnosis and treatment per se.

Health Care Facilities

6. Where possible, mental health care for individuals during emergencies should be delivered by trained mental health professionals in the context of general medical care. Because this may not be possible during emergencies, health care facilities should ensure that their staff receive supplementary training in detection and management of mental health problems, including training in treatments that are designed to restore competency when possible.

7. Health care facilities should make mental health screening and prevention part of their “universal” emergency care. This could include development and implementation of a few key questions to identify quickly individuals who need additional mental health services.

8. Standards for compulsory evaluation, treatment, and hospitalization should be defined in emergency training manuals, including explanations of the need to provide the least restrictive care that is consistent with individuals’ safety. Administrative personnel in charge of emergency medical responses should be familiar with these procedures.

Emergency Responders

9. Responders must be attentive to the need to protect the privacy of mental health data in emergencies. Individuals with mental health disorders are entitled to strong privacy protections. Identifiable medical records should not be “flagged” in a way that makes it externally obvious that they contain psychiatric records. Only the minimum information needed to ensure good-quality mental health care should be disclosed to those having a need to know (eg, caregivers, mental health providers).

10. Patients with mental illnesses should not be segregated from patients with other illnesses unless there are risks related to patient health and safety or enhanced supervision or support of mental health patients can be achieved in a separate setting.

11. When possible, individuals with known chronic mental disorders should not be separated from other family members. As in nonemergencies, the support provided by family members and existing community structures should supplement treatment.

12. Educational and other health communication materials (eg, posters, manuals) directed at populations undergoing emergencies should be created in such a way as to attempt to normalize

the occurrence of mental health issues during emergencies and to suggest that care for mental health problems is part of “routine” care during emergencies.

Individuals and Families

13. Individuals whose mental health care requires consistent medication administration or whose condition is susceptible to relapse, should at all times carry with them information about their condition and emergency treatment.

14. Families should develop their own plans to ensure continuity of care for relatives with a mental disorder or impairment during emergencies. This process may include establishing emergency contacts in the event of family separation and drafting detailed instructions explaining the care needs of mentally impaired relatives.

CONCLUSIONS

Individuals with mental disorders constitute a vulnerable population at high risk for unequal and insufficient treatment during complex emergencies, with possibly irreversible or fatal consequences. They face unique ethical issues resulting from harm that arises from lapses in treatment, stigma associated with mental disorders, and challenges associated with respecting individuals’ autonomy. A variety of steps involving individuals themselves, their families, health care providers, and emergency preparedness systems may ensure the provision of more equal and effective care. These measures should be integrated into emergency preparedness efforts to ensure that the needs of individuals with mental disorders are met.

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