Do Individuals Living with HIV know how to Access Resources in Order to Safeguard their Health in the Event of Statewide Emergency Situations?

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Abstract
There has been a significant increase in the number and severity of disasters over the past decades as is noted in the Centre for Research on the Epidemiology of Disasters' Emergency Events Database (EM-DAT). Access to care during such events is critical for vulnerable populations, especially those with communicable diseases such as HIV. As such, inability to access antiretroviral medications, safe food, housing, and transportation may disproportionately affect People Living with HIV (PLWH). This is especially so, because PLWH are both more likely than the general population to experience adverse effects from disasters and face multiple stigmatizing barriers to care.

Methods: A cross-sectional survey was self-administered to a convenience sample of 53 volunteers who were in attendance at a World AIDS Day event in Washington, DC. This pilot study utilized scenarios to examine what PLWH would do if they ran out of medication and food in the event of an emergency situation such as a natural disaster or catastrophic event. The survey also asked about PLWHs’ housing and transportation concerns in emergency situations.

Results: Analyses revealed that all areas assessed would pose a difficulty for PLWHs. Furthermore, inability to access medication (88%) and the lack of knowledge about how to access medication (92%) during a natural disaster were consistently stubborn issues.

Conclusions: Findings suggested that this cohort of PLWH in DC might not be prepared for emergencies. Similarly, they do not know where to access the assistance needed to prevent health complications during emergencies and disaster situations. The results highlighted some reasons for vulnerability of PLWH in this geographical location. More planning and education are needed to safeguard the wellbeing of PLWH, lessen PLWH’s health vulnerabilities, and enhance supportive services for PLWH and their caregivers during emergency or disaster situations. Significant implications are discussed for future prevention, intervention, practices, and research as the nation moves to address the goal of “Ending HIV by 2030.”
**Keywords:** HIV; Health; Emergency Situations; Safeguard

**Introduction**

Being prepared for a disaster or emergency situation is important for everyone, but especially for individuals who are ill, including people who are living with HIV (PLWH). PLWH must go beyond preparing for disaster situations. They must also prepare for the disruptions to their medical care caused by a disaster. This is especially so, because disasters often occur with little or no notice. While the impact of HIV is generally well-documented and understood, considerably less attention has been given to the unique needs of PLWH in disaster situations. The least of these needs is the spread of the disease due to inaccessibility to medication, potable water, and safe food handling practices. In general, people already infected with HIV are at greater risk of physically deteriorating during an emergency. This is so because they are more prone to suffer from disease complications and death as a consequence of limited access to food, clean water, and good hygiene; than are people with functioning immune systems.

It has been well-documented that stronger and more destructive storms will become the new normal [1-5] and as such, we are forced to focus on preparing "whole communities" long before a catastrophic event occurs. Data [6] reveal that of the over 330 million persons living in the U.S., nearly 60% of American adults have not practiced what to do in a disaster or emergency situation. A mere 39% of the population reported that they have developed an emergency plan. All this, despite the fact that 80% of Americans live in counties that have been hit with a weather-related disaster since 2007. Furthermore, displacement as a result of a disaster may result in a lack of access to medication and may exacerbate the fragile health of individuals suffering from communicable diseases such as HIV. Overall, people who are unable to access their HIV medication are in danger of secondary infections and have a higher risk of transmission to others if they do not continue their daily antiretroviral therapy. Emergency and disaster situations may also serve to bring populations in areas that have low HIV prevalence rates into contact with those from areas with higher HIV rates. To prevent HIV from persisting and expanding beyond the disaster incident, a response to HIV should be incorporated into overall emergency response strategies.

While we have made significant gains in helping stymie the spread of HIV, it has remained a stubborn disease. Currently, more than 1.1 million people in the U.S. are living with HIV and 1 in 7 (14%) is unaware of having the disease [7]. Despite the many advances in HIV prevention, current CDC data [8] show that over 38,500 Americans became newly-infected between 2012 and 2016. It is important to note that the annual number of new HIV diagnoses has remained stable in recent years in the U.S. and its territories [9]; whereas the frequency and intensity of natural disasters have increased exponentially [10,11].

The rationale for this paper is that HIV is no longer a “death sentence,” but instead, a manageable chronic disease. Despite this, the disease continues to affect human health and threaten both the individual's and community's safety during emergencies and disasters. Furthermore, a significant number of the U.S. population affected by HIV is also geographically located in areas that are prone to disasters thus, further exacerbating PLWH’s vulnerability to treatment failure. The aim of this study was to examine whether PLWH knew where to access resources in order to safeguard their health in the event of a statewide emergency or disaster. Findings would then be used as a springboard to update policies and procedures in this regard, as warranted.

**Methodology**

We used convenience sampling to collect data from participants who attended an event in Washington, DC commemorating annual World AIDS Day. Over 300 persons attended the day-long event. Participants attended an interactive presentation entitled, "Emergency Disaster Preparedness for Persons Living with HIV". After the presentation, 53 persons volunteered to complete a self-administered survey. The survey posed nine questions. Three questions were part of a case scenario regarding how participants would respond to emergencies or prolonged disasters without adequate medication and food or access to housing and transportation. We also queried participants about their abilities to access these resources and remain healthy in an emergency or disaster situation. Water bottles were given as an incentive to each participant who returned a fully completed questionnaire.
Results and Findings

Sample and General Questions

More than 42% of the participants identified as male, 50% as female, and 8% identified as transgender. Almost 63% reported living below the poverty rate. All of the participants reported being HIV positive for three or more years. In this sample, almost 80% of respondents shared that they currently did not have enough food in their homes to meet their needs for at least three days. Almost 82% responded that they did not have an emergency supply kit to take with them in case of an evacuation. This percentage is much higher than CDC’s [12] findings that 48% of Americans reported not having emergency supplies and 44% reported not having first aid kits.

Scenario 1: We presented the following case scenarios and posed specific questions to participants: “The city is blanketed by almost 18 inches of snow which then freezes over as temperature drops and ice storms take over intermittently for three consecutive days. Temperature remains below 5 degrees Fahrenheit and all local, state and federal governments are closed for a total of 4 days. Rolling power outage began on day two of the snow storm and continued for six more days.” When asked to rank order the importance of having specific items available on hand during an emergency, participants reported the following order: medication (45%), followed by food (30%), housing (15%), and transportation (10%). When queried, “Which of the following is an emergency for you? Check all that apply,” the group revealed the following: Not able to get HIV medications for a week (89%); lack food for a week (83%); unable to find housing for a week (75%); and, no access to public or private transportation for a week (56%).

Scenario 2: We also asked, “You are required to eat before taking your medication but have run out of food during the second day of the storm. What would you do? Just over one-third (35%) reported taking the medication without food; 28% would not take the medication at all; 23% reported "not sure"; and 14% would go to a neighbor to ask for food.

Scenario 3: For the final query we asked; “You forgot to fill your prescription and have run out of medication during the third day of the storm. What would you do?” About 41% reported that they would call the Department of Health; almost 23% would call a friend; about 18% would do nothing; 10% would call their doctor; and 8% would go to the drug store.

Conclusions

The results of this pilot study show that this sample of PLWH in the face of emergencies is at risk of becoming further medically compromised. Emergency preparedness typically focuses on addressing the causes of the emergency with a view to avoiding its recurrence or mitigating its impact while simultaneously strengthening resilience. These efforts should be extended to vulnerable and at-risk populations whose coping mechanisms and capacity to respond to threats make them even more vulnerable to disaster-related dangers. For example, the Department of Homeland Security recommends that emergency kits should be stocked with at least a three-day supply of non-perishable food items as part of their “Build A Kit” [13] initiative for emergency situations.

In this sample, almost 80% of respondents shared that they currently did not have enough food in their homes to meet their needs for at least three days. Good nutrition, food security, and food sanitation and safety are all critical protective factors in preventing secondary infections for PLWA. HIV infection damages the immune system, which can lead to lower food intake, reduce appetite, and interfere with the body's ability to absorb food. It is during disasters that food insecurity is often of great concern. This is so because, coupled with the stress of a disaster, hunger can lead to malnutrition. We also know that HIV is more virulent in the malnourished person. Unsanitary conditions such as crowding and poor hygiene; not washing hands properly when handling food; and unsafe cooking practices further burden the disease and exacerbate an already strained immune system.

Also, the majority of respondents in this study indicated that they would contact the Department of Health (DOH) for help with replenishing their medication. In speaking with the leadership for the city’s DOH HIV program, we were informed that the department opens during regular business hours and is closed on weekends, holidays, and during storms as recommended by the city's administration. The most helpful solution for this situation (i.e., go to a drug store/pharmacy) was the least reported. Pharmacies are most likely to be opened and would therefore be accessible. However, pharmacies may not be the access point for that patient’s medications if the PLWH’s electronic patient records are not linked to the pharmacy's electronic patient system.

HIV treatment involves taking a combination of medication called antiretroviral therapy (ART) which slows the progression of the virus in the body. ART
reduces the viral load in the blood and body fluids and this in turn reduces your chance of transmitting HIV to
others. If doses are missed over a period of time ART will
not be effective in reducing viral load and protecting the
immune system. Once viral load is not fully suppressed,
HIV has a chance to change and become resistant to the
medication that has been prescribed. Devastatingly, it
might also mean that the strain of HIV being treated may
also become resistant to the entire class of medications
that are similar to the ones the patient is taking. It is
important to note that some ART’s require food in the
stomach and gut for the body to absorb them properly
and to reduce side effects of stomach irritation, including
indigestion, stomach inflammation or ulcers.

Thus, the conditions generated by emergencies, such
as medication non-adherence due to food insecurity can
serve to increase an individual’s vulnerability to HIV. This
especially so depending on the stage of the infection, the
extent to which the above protective factors are enhanced
and/or the risk factors are mitigated and where the levels
of infection are already high. As a result, PLWH’s
vulnerability to treatment failure is further exacerbated.
Because of their compromised immune systems, lack of
medication, poor hygiene, limited access to food, and
other social and psychological support, PLWA are at
increased risk for opportunistic infections. Accordingly,
they are at greater risk of physically deteriorating during
an emergency or disaster situation. As a result, health
complications and possibility death are ever-present
dangers. Moreover, the conditions generated by
emergencies can serve to increase a person’s vulnerability
to HIV, depending on the stage of the infection, especially
in situations where levels of infection are already high.

Physical injury and death after a disaster tend to be
immediate, happening within minutes of the event onset.
Priorities are often to supply water, food, and shelter; and
address sanitation and life-threatening health needs.
Because HIV is relatively invisible, it is not considered an
immediate threat to life. However, vulnerabilities and
health risks of PLWH will increase in a disaster situation if
access to HIV prevention, treatment, care and support are
not addressed and ensured [14]. We know for example,
that in an emergency, there is often a break down in basic
services that are essential for preventing communicable
diseases including HIV. During the acute phase of an
emergency, the absence of adequacy of services
facilitates HIV transmission through lack of universal
precautions. The unavailability of condoms and the HIV-
related stigma further burdens vulnerable individuals by
making them unable to practice preventive behaviors or
access treatment and support. Additionally, under-
resourced communities and households have fewer
means to protect themselves from, and to cope with, the
consequences of emergencies and disasters. Persons who
do not have access to HIV medication are at increased risk
of infecting others if they do not continue on their daily
antiretroviral therapy.

As a group, vulnerability to suffering negative effects
from emergencies like the scenarios presented in this
study, increase among people with HIV who are ill and not
prepared. It is, therefore, necessary to support this
vulnerable group of individuals in order to increase their
resilience to emergencies and disaster risks when they
strike. Support involves specific training and awareness-
raising activities on emergencies and natural disasters
and the measures that need to be taken to be better
prepared, before, during and after these situations.
Contingency plans that need to be built at individual,
family and community levels should also be included. This
approach will empower PLWH and facilitate their active
participation throughout planning and rescue processes.

Emergency preparedness plans should, therefore, be
developed in order to minimize the adverse health effects
of a disaster. Plans should ensure that organization and
delivery of emergency responses for medically vulnerable
populations such as PLWH are timely, appropriate and
sufficient. Such preparedness plans should be part of a
long-term development strategy and not introduced as a
last minute response to the unfolding emergency. In the
case of HIV, such preparedness means that all PLWH, as
well as their care providers and care communities, will
have received a basic preparedness training to include
where to access medication, food, housing and
transportation. To be effective, training should occur
before an emergency or disaster situation occurs.
Additionally, as part of their cadre of competencies, all
responders should receive basic training about infectious
diseases including HIV as well as non-discriminatory
behaviors towards patients who are HIV positive and
their caregivers.

While the impact of HIV is generally well-documented
and understood, considerably less attention has been
given to the spread of, or the prevention, management
and care of HIV in the context of emergencies and
disasters. While infrastructure and physical mitigation
plans are vital to recovery and rehabilitation, efforts to
prevent new HIV transmission and providing support for
those already affected in the midst of an emergency are
equally important disaster responses. Providing essential
HIV prevention, treatment and care services, in particular to enhance individuals’ ability to have access to antiretroviral drugs (ARVs) for prevention and treatment of HIV infections, is vital.

**Lessons Learned**

- Several lessons were learned from this study. They include that the majority of people who participated in the study do not know how to access resources in order to safeguard their health in the event of statewide emergency situation. There is an urgency to identify and implement institutional and public policies to help insure that available services and resources are provided for vulnerable communities at the point of need.
- We also learned that engaging the community through an initial presentation of the issue at hand and in so doing provided a heightened sense of awareness about the issue at hand was a good strategy. And, when coupled with an incentive, we were rewarded 100% participation from the community we aimed to reach.
- This study may have been more immediately impactful for the community to be served had it been coordinated with local stakeholders. Because of bureaucracy, progress can often stymie urgent responses. Thus, having the City’s leadership (department of health, office of disaster preparedness, pharmacy association, and other requisite stakeholder groups) participate up front with the researcher would have been strategic. Immediate actions could have been taken to begin to address the disparity unearthed in this study with to aim of beginning to address it.
- While local resources are readily available in this City, there is a lack of connection between the community and these resources to insure access for this vulnerable group of individuals. An increase in whole community awareness needs to be raised and opportunities to strengthen community emergency disaster resiliency improved. Pharmacies and drug stores as well as academic institutions and religious organizations are untapped community resources and should be included at the community level to support PLWH.
- More needs to done at the local government level to educate vulnerable communities and address the social and structural determinants of emergency related community resilience. This approach should help insure that PLWH become more informed and vocal about safeguarding their health during emergencies.

**Summary**

There is a predicted increase in disasters and associated demand for emergency medical services. Regardless of crisis, it is critical that contingencies are in place to ensure that health services are maintained. Linking local HIV service programs with pre and post disaster efforts is a major factor in the stabilization of HIV prevalence in our cities. Successfully coordinated responses to include preventive measures by predictive early warning systems, adequately trained first responders and patients with HIV; and insurance that adequate and appropriate supplies specific to HIV are pre-positioned can all serve to help minimize the impact of these emergencies and disasters.

These findings show that there is an urgent need to incorporate the HIV response into the overall emergency response in the city where this pilot study was conducted. If we are unable to accomplish this, the numbers of people infected with HIV could easily increase thereby creating an unnecessary crisis. Furthermore, if not addressed, the impacts of HIV will persist and expand beyond the crisis event itself, influencing the outcome of the response and shaping future prospects for rehabilitation and recovery. Consequently, unless the HIV response is part of the wider response, all efforts to address major emergencies or disasters will be insufficient. It is our responsibility as care providers in the field of emergency and disaster management to develop awareness of existing policy and practice in emergency programs that aim to safeguard the health of our communities. The bottom line is that an infectious disease threat anywhere can become a disaster everywhere!

**Limitations of the Study**

The small sample size reduces the power of the study and increases the margin of error; thus, forcing us to settle for less conclusive results. While the reliability and validity of the results were not established, the implications of the findings of this study render it meaningful because of the significant issue being researched.

**References**


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