Kidney health for all: preparedness for the unexpected in supporting the vulnerable

Li-Li Hsiao1, Kavya M. Shah1, Adrian Liew2, Dina Abdellatif3, Alessandro Balducci4, Ágnes Haris5, Latha A. Kumaraswami6, Vassilios Liakopoulos7, Siu-Fai Lui8,9, Ifeoma Ulasi10 and Robyn G. Langham11; for the World Kidney Day Joint Steering Committee12

As the rate of natural disasters and other devastating events caused by human activities increases, the burden on the health and well-being of those affected by kidney disease has been immeasurable. Health system preparedness, which involves creating a resilient system that is able to deal with the health needs of the entire community during times of unexpected disruptions to usual care, has become globally important. In the wake of the COVID-19 pandemic, there is a heightened awareness of the amplification of negative effects on the renal community. Paradoxically, the complex medical needs of those who have kidney diseases are not met by systems handling crises, often compounded by an acute increase in burden via new patients as a result of the crisis itself. Disruptions in kidney care as a result of unexpected events are becoming more prevalent and likely to increase in the years to come. It is therefore only appropriate that the theme for this year’s World Kidney Day will focus on Kidney Health for All: preparedness for the unexpected in supporting the vulnerable.


KEYWORDS: dialysis care; disaster response; emergency preparedness; kidney health; natural disasters; public health; social media

Copyright © 2023 World Kidney Day Steering Committee. Published by Elsevier Inc., on behalf of the International Society of Nephrology. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

This article is being published in Kidney International and is being reprinted in Kidney Reports. The articles cover identical concepts and wording, but vary in minor stylistic and spelling changes, detail, and length of manuscript in keeping with each journal’s style. Any of these versions may be used in citing this article.

Note that all authors contributed equally to the conception, preparation, and editing of the manuscript.

The United Nations Office for Disaster Risk Reduction defines a disaster as “a serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability and capacity, leading to one or more of the following: human, material, economic and environmental losses and impacts.”1 The global incidence of natural disasters is increasing, with the rate of disasters growing by at least 10-fold in one report from 1960 to 2020,2 with attendant increases in mortality, injuries, diseases, and disabilities. In 2021, natural disasters affected 101.8 million people worldwide, accounted for over 10,000 deaths, and caused approximately USD$252 billion in economic losses.3 In the same vein, at the end of 2021, 89.3 million people worldwide were forcibly displaced from their homes because of conflicts, violence, or fear of persecution and human rights violations, totaling more than twice the 42.7 million individuals displaced a decade ago and the most since the World War II.4 Disasters disproportionately affect those living in developing nations or low-income communities. The United Nations explains that the loss of capital assets and infrastructure such as schools can cause the poor to fall into “poverty traps,” which are multigenerational setbacks that can be very difficult to escape.5 Disasters also mostly harm groups that experience intersectional social disadvantages such as a low socioeconomic status and ethnic/racial discrimination.6 Governments have a responsibility to uplift these groups during disaster response and recovery to ensure that existing inequalities are not exacerbated. With such a scale of impact on the community, there is a clear need to better plan and prepare for disasters of all scales in an attempt to minimize the effects that disruption to daily life brings to health and well-being.

Types of natural disasters and other unexpected events

Natural disasters come in many forms, so it is important to understand the basics of common
disasters to develop a versatile preparedness strategy. Floods are the most common type of natural disaster, affecting over 2 billion individuals globally from 1998 to 2017. Floods occur when dry land is submerged by a large influx of water such as heavy rainfall and pose a threat in areas close to a coast or body of water. Tropical cyclones such as hurricanes and typhoons are another common water-based natural disaster, affecting an estimated 726 million people from 1998 to 2017. Cyclones require moist air and wind to form, and thus occur in the Atlantic, Pacific, and Indian oceans. Earthquakes are a sudden land-based natural disaster characterized by the ground shaking and landslides. Earthquakes typically occur in areas atop a fault line in the Earth’s crust and have impacted over 125 million people from 1998 to 2017. One especially dangerous byproduct of earthquakes are tsunamis, which are fast-rising waves with powerful currents that can cause significant damage to coastal areas. Natural disasters that are highly localized to certain regions of the world include volcanic eruptions, of which 75% occur along a belt in the Pacific Ocean known as the “Ring of Fire,” and blizzards, which are common in Antarctica and the northern regions of Asia, Europe, and North America.

Unexpected events outside of natural disasters can also cause major distress and occur at different levels of society. National and international events to prepare for include war, famine, and infectious disease outbreaks. Although war and famine may be initially predictable, they can be difficult to prepare for as they last for an extended period and can affect millions of people at once. The coronavirus pandemic is a timely example for the need for worldwide preparedness; one study finds that an inadequate response to coronavirus disease 2019 (COVID-19) likely resulted in around 200 thousand avoidable deaths in the United States in 2020 alone. Disastrous unexpected events can also occur on a more local scale. Unexpected road closures, power and internet outages, and interruptions to water supplies can not only be a nuisance in a person’s day-to-day life but also be life-threatening. One study found that road closures and infrastructure disruptions during marathons increased the risk of death from heart attacks, as many people en route to hospitals were unaware of these closures beforehand. Regardless of the scale of the event, it is important to prepare for unexpected events outside of natural disasters.

Preparing for kidney care during future disasters

In the wake of the COVID-19 pandemic, significant work is being done to better understand and improve health system preparedness and resilience. It was clear that those with noncommunicable diseases (NCDs) were more likely to develop serious illness and die, as the needs of providing and prioritizing ongoing complex care for this patient cohort were deprioritized in favor of acute health responses. There is a real need for health care systems and jurisdictions to develop more resilient systems. Reflecting on the lessons learnt from Ebola, Kruk et al. note that resilient health systems are able to deliver everyday benefits and positive health outcomes for all, not only during a crisis but also in its aftermath. The term “resilience dividend” indicates improved performance in both bad times and the good.

The main recommendations from the Lancet COVID-19 commission succinctly outline three high-level areas for health system development: (i) strengthening national health systems and increasing investments in primary health care and public health; (ii) national pandemic preparedness plans; and (iii) financing for sustainable development and green recovery plans. Clearly, with the complexities of kidney disease and NCDs as a whole, health system resilience requires overarching multisystem policies and frameworks by which we can adequately prepare for and recover from high consequence shocks. A framework for public health emergency preparedness (PHEP) that can easily be adapted and applied universally is key, enabling countries or health systems to more easily modify existing plans to suit the type of disaster and environment. Conventionally, health emergency responses did not include kidney or NCD care. During the COVID-19 pandemic, people living with NCDs faced worse outcomes than those without. With regard to kidney disease, a study conducted by the End-Stage Renal Disease National Coordinating Center found that deaths among patients with kidney failure exceeded the expected numbers by 6953–10316 during the early phases of the COVID-19 pandemic, and excess mortality was also observed in a subgroup analysis of patients receiving solid organ transplants. A retrospective cohort study in England also found that patients with chronic kidney disease faced a high 1-year mortality risk burden during the COVID-19 pandemic. There is an increasing
understanding that disruptions during these periods expose people living with NCDs to greater consequences, including death.

A framework of PHEP has been developed by a Canadian team of researchers that is empirically derived, end-user informed, and further refined to ensure practice and policy relevance for local/regional public health agencies. This framework captures the complexity of the system required and ensures that clinical care for pre-existing chronic disease is available and preserved because of the PHEP's interconnectedness and flexibility (Figure 1).

The annotated figure identifies the areas for preparedness specific to kidney disease, all integrated under a system-wide response. Ensuring early identification and integration of kidney care needs in the preparedness phase and confirming essential supplies and supply chain for medicines and technologies, as well as developing robust and personalized plans for patients, are all essential in handling early disaster phases. Furthermore, it is clear that responses to disasters must integrate kidney disease in initial assessments by mapping kidney disease services provision and focusing service delivery on primary care. Also, critical support of workforce requirements and management of mental health issues in patients and staff are central. Evaluation needs to be ongoing, both during the crisis and in the recovery, exploring ways to improve at all opportunities and addressing identified gaps.

A key component of PHEP, especially highlighted by the "Community Engagement," "Collaborative Networks," and "Communication" touchpoints described below, is the importance of disseminating accurate and accessible information to the public. An increasingly powerful approach for distributing information quickly and to a large audience is the use of digital technologies and social media. Digital media tools such as online blogs and medical forums have been great resources for posting timely information and critical updates about the status of a public health emergency. Social media platforms like Facebook, YouTube, Twitter, WhatsApp, and Instagram are highly accessible for anyone with a smartphone, and each boast millions of users to communicate with. Many health care professionals and advocacy organizations use social media to engage with and inform patients, and it is clear that digital communication will be the path forward for providing kidney health information for all. However, an important concern is to ensure that disinformation, particularly about public health emergencies, does not spread via these digital tools. Ensuring accurate and official information for disaster preparedness is widely disseminated digitally, whereas curbing the circulation of incorrect or misleading content will be an imperative in planning. Governments and organizations can mitigate the spread of disinformation by working with social media companies to invest in the development of algorithms that identify “fake news,” and by strengthening policies that strike down fake or malicious online accounts.

Clearly, kidney disease management in disaster situations should not stand alone but be part of any PHEP framework. Importantly, local and international renal societies and NGOs, as well as patient associations, have a pivotal role in how patients with kidney disease manage their care and are treated during emergencies. Close collaboration with health authorities and dialysis providers is needed.

The Public Health Emergency Preparedness (PHEP)

One such preparedness framework, among others described, is this framework described by Khan et al., which details 11 essential elements that have touchpoints where integration with other health services can occur, ensuring optimal service delivery for patients (see Figure 1). This framework describes high-level components of ensuring a health system that considers all aspects of care both during and in the recovery from a disaster—regardless of the level of wealth or resourcing in the community. It also applies to low- and middle-income countries as in high-income ones. The details of the 11 steps are as follows:

(i) Governance and leadership—fundamental to PHEP. Structures are integrated vertically and horizontally, including essential areas in the health and non-health sectors. Partnerships and accountabilities support coordination for the renal community, including power companies, supply chains, and the many layers of the health care system.

(ii) Planning process—Involves developing a dynamic, collaborative preparation process emphasizing the value of due process in public health preparedness that includes NCD care. Roles, responsibilities, relationships and engagements, and organizational structures and functions are clarified.
(iii) Collaborative networks—linking to the planning process, this entails developing relationships, partnerships, and strong networks. Collaboration supports readiness, response, and recovery through various levels in the system and includes
other stakeholders such as clinical care practitioners, emergency care management, government, nongovernmental organizations, or the private sector. It should emphasize interconnectedness within and outside public health.

(iv) Community engagement—promotes inclusivity and engenders community understanding. Community risks, assets, and values are incorporated, facilitating transparency and trust between the community and the public health agencies. This reinforces the resilience of the system. Ensuring patient self-care and preparedness is of critical importance.

(v) Risk analysis—is important to understand the risks for the communities and to access and analyze the information that helps appraise planning. Risk analysis strengthens planning and decision-making. Existing social risk factors such as poverty, disabilities, or morbidities someone may have before a disaster put them at higher risk and more vulnerable. This applies to all patients with kidney disease, be it chronic kidney disease, acute kidney injury, dialysis, or transplant patients.

(vi) Surveillance and monitoring—surveillance should be robust to provide information promptly to key stakeholders and the community. It promotes awareness in advance as the main element of surveillance and monitoring includes early detection and “early warning” alerts of emergent risks to relevant health authorities and the wider system. This increases a systems approach to data collection, linking many data sets such as electronic health records, drug utilization, and community health records.

(vii) Practice and experience—include exercises, simulations, drills, and/or practice to build capacity for response and feedback, and also practice tests and plans to identify gaps and weaknesses in the process.

(viii) Resources—centered on physical, structural, and financial resources, essentially capacity for systems and infrastructure to help elements of PHEP.

(ix) Workforce capacity—is critical, and well-trained and knowledgeable staff should form the social infrastructure for the system. Staff need education and training in preparedness, including how to support direct patient need and preparedness.

(x) Communication—should be clear and consistent with understandable information to create awareness across the networks and the public to deliver information promoting public action or behavior change or providing guidance for the health care workforce. Optimal use of social media, with important and relevant messaging planned early to counteract false messages.

(xi) Learning and evaluation—learning is usually flexible during emergencies, and it is connected to other elements of PHEP like surveillance and monitoring. A critical aspect of learning is through understanding the patient perspective toward disaster. One descriptive study evaluated patient thoughts during disasters and found that major themes included feeling unprepared and concerns with managing the disease. Evaluation helps build resilience in the system and is crucial to recovery and building back better.

Disruptions in kidney care—specific outcomes

Disruptions to dialysis care. Individuals on dialysis are a particularly vulnerable group with respect to disasters. The critical consequences of a lack of access, coupled with an exponential increase in demand for dialysis as a result of trauma and injury from unexpected events, can lead to a critical failure of kidney services in an affected area. In 2005, the aftermath of Hurricane Katrina resulted in the closure of 94 dialysis facilities in the Gulf Coast of the United States, disrupting the continuity of life-sustaining treatment for existing patients on dialysis. Earthquakes in the Marmara region of Turkey in 1999 and Kashmir in 2005 led to a large spike in the number of patients with acute kidney injury due to crush injuries needing kidney replacement therapy. During the Marmara earthquake, 477 patients with acute kidney injury had emergency dialysis, most of whom would have died if dialysis treatment had not been available. The COVID-19 pandemic has further highlighted that caring for patients with kidney disease is particularly challenging, especially with regard to dialysis patients who require complex and specialized team-based treatments in a system already overburdened with patients with COVID-19. Many hospitals dedicated most of their inpatient capacity to patients with acute COVID, admitting only those patients with other illnesses who were
critically ill, with subacute inpatient care deferred to outpatient and home-based care.

In 2020, an online survey was conducted in Egypt to study the effects of the COVID-19 pandemic on the dialysis population at the Cairo University Children’s Hospital. With nearly 40% of patients traveling from outside greater Cairo and relying on multiple modes of public transport, almost half of the patients reported missing or arriving late for dialysis sessions. The study further reported that the financial consequences of quarantine requirements led to nutritional decline and had a significant psychological impact on patients and their caregivers. In India, the challenges due to the COVID-19 pandemic were enormous. With 3 months of lockdown where no public or private transportation was available, dialysis patients relied on the help of family and friends to travel for treatment. Staff often lived in medical units to provide treatment, and there was an overwhelming shortage of personal protective equipment. As in Egypt, the financial effects of severe lockdowns led to a lack of proper nutrition and medicines.

The vulnerability of dialysis patients can also be seen in man-made disasters such as war. Since the beginning of the Russian invasion of Ukraine, Ukrainian dialysis patients have suffered tremendously under the uncertainty of dialysis provisions coupled with the life-threatening horrors of the war. In Ukraine, there are currently over 10,000 dialysis patients, and more than 1500 individuals are living with a transplanted kidney. More than 800 medical facilities have been damaged since the beginning of the war, many of which are dialysis centers. Initial reports of extremely critical access to dialysis consumables were soon followed with reports of patient and staff cut off from dialysis centers because of missile attacks, bombardments, and active fighting on the ground. Many displaced patients and staff lived directly in dialysis centers. Although it has been recorded that some of these patients died, the outcome for most is unknown.

Disruptions to transplantation. Transplant services are often suspended in times of crisis, which leads to stress on the health care system. This was certainly the case for many countries in the early stages of the COVID-19 pandemic, with suspensions of waiting list activation in the setting of recent infections, some still ongoing. Also, access to essential immunosuppressive medications for kidney transplant recipients is often disrupted in the wake of a disaster, increasing the risk of rejection and allograft loss. This was appreciably experienced in Puerto Rico during Hurricane Maria in 2017, where the limitations in power, transportation, and communications posed significant challenges in ensuring that immunosuppressive drugs were delivered to patients.

A recent publication from the DESCARTES working group and ethics committee of the European Renal Association details the perils faced by kidney transplant recipients and kidney transplant programs in times of disaster. The authors strongly advocate for continued transplant services in addition to detailing the various logistic problems that are faced in times of disaster. However, they also note that postponing transplantations from living donors may be justified to reduce the risk of nosocomial infection and recommend early facility discharge for donors and recipients whenever possible. A number of concrete proposals are suggested, including patient education, adaptation to immunosuppressive therapy, and ensuring availability of local operational services. Importantly, the DESCARTES working group concludes that it is difficult to assess if and when it is appropriate to shut down kidney transplant programs during period of disaster but argues that “denying a life-saving therapy” is rarely justified.

Disaster response—optimizing care

As discussed, the dialysis population has been one of the most visibly affected groups during the COVID-19 pandemic, representative of a more general lack of disaster preparedness on a global scale. Many dialysis units were severely impacted at the beginning of the COVID-19 pandemic with problems managing schedules and keeping patients safe. With time, a move toward telehealth improved communications, with increased attention to health literacy and multilevel information on how to handle acute COVID, distancing and immunization schedules. Many units implemented the rationalization approach, involving goal-oriented workflows to meet the needs of acute kidney injury, distancing requirements, and supply issues. In some areas, COVID-positive patients were cohorted for treatment in individual units. Many health systems thoroughly evaluated transplant recipients for risk of infection and used telemedicine for post-transplantation follow-up. From most reports, it is clear that transport issues were the most difficult to address. Although home dialysis might be seen
as preferable treatment to address the problem of transport to dialysis units, in some situations, it is the uncertainty of power and water supply that affects all. Of note, after the Chi-Chi earthquake in Taiwan, automated peritoneal dialysis patients were switched to continuous ambulatory peritoneal dialysis as electricity supply became a problem.33 An international survey of the preparedness and management of the COVID-19 pandemic by dialysis units around the globe found disparate and patchy responses, though most had disaster plans in place before.34

**Conclusion and recommendations**

Regardless of the scale of the event, optimal renal care demands a level of preparation for unexpected events. As disruption in kidney care is becoming more prevalent and likely to increase in the years to come, robust plans, personalized for patients, that are constantly reviewed and tested should be an essential part of a well-functioning kidney service.

For the community as a whole, a comprehensive, adaptive PHEP framework with integrated kidney disease (NCD) emergency response may help reduce the difficulties experienced during disasters and aid in the capacity to recover services. Health systems need to be adaptive, robust, and resilient, incorporating the essential PHEP elements to function optimally in and out of emergency/disasters. In the wake of the COVID-19 pandemic, we must continue to advocate for kidney disease to be included and integrated into preparedness plans, pre-emptively highlighting the importance of providing business-as-usual ongoing care for kidney patients during unexpected times.

**APPENDIX**

The World Kidney Day Joint Steering Committee includes co-authors Li-Li Hsiao, Dina Abdellatif, Alessandro Balducci, Agnes Haris, Latha A. Kumaraswami, Vassilios Liakopoulos, Siu-Fai Lui, Iffoema Ulasi, and Robyn G. Langham, as well as Alice Poidevin and Anne Hradsky.

**DISCLOSURE**

All the authors declared no competing interests.

**REFERENCES**


33. Hwang SJ, Shu KH, Lain JD, Yang WC. Renal replacement therapy at the time of the Taiwan Chi-Chi earthquake. Nephrol Dial Transplant. 2001;16(suppl 5):78–82.