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Challenges and Solutions for Data Collection Related to Nephrological Problems Following Disasters

Serhan Zubeyde Tuğlular[1], Savaş Öztürk[2], Rümeyza Kazancıoğlu[3], Mehmet Şükrü Sever[3]

[1]Department of Nephrology, Marmara University Faculty of Medicine, Istanbul, Türkiye
[2]Department of Nephrology, Istanbul University Faculty of Medicine, Istanbul, Türkiye
[3]Department of Nephrology, Bezmialem Vakif University Faculty of Medicine, Türkiye

ABSTRACT

Although collecting scientific data during disaster conditions may be very challenging and not considered a priority, it is crucial since it may serve to shed light on similar future disaster conditions. The primary obstacles in data collection fall into 2 main categories: (i) the recording process itself and (ii) the reliability of the test results. During and after crisis periods, data collection is complicated by various factors. These include a sudden and significant surge in patient numbers, disruptions in hospital operational systems, health-care professionals experiencing burnout, inadequate examination of incoming disaster victims, rapid patient transfers to other health-care facilities, and infrastructural damage affecting the operation of hospital health information systems. These challenges collectively lead to inaccuracies in hospital data collection and storage processes. The reliability and interpretation of even the basic test results may be hampered by functional disruption of the laboratory systems, mixing of patients' lab results due to overburden of patients, and lack of identification information as well as incorrectly abnormal values due to inadequate preanalytical and analytical processes. This opinion article discusses health-care professionals' data collection challenges regarding kidney problems during large-scale disasters and suggests solutions to overcome these problems.

Keywords: Clinical nephrology, data collection, disaster nephrology

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INTRODUCTION

Natural and man-made disasters can have devastating consequences for affected communities. Besides the sudden destruction and loss of life, the overwhelming influx of disaster victims can overload health-care systems in the affected regions/countries. Although the link between disasters and the kidneys has first been defined for acute kidney injury in 1941, since then the world has faced many natural and man-made disasters and it is now well documented that threats to life occur across the spectrum of patients with kidney diseases at times of disasters.[1,2]

Although collecting scientific data during disaster conditions very challenging and not considered a priority, it is crucial since it may serve to shed light on similar future disaster conditions.[3] Data collection serves dual purposes: guiding immediate clinical care and facilitating quality assessment to identify strengths and weaknesses during a disaster. The collected information can serve as valuable knowledge for future disaster preparedness and responses. Furthermore, there is not any experimental model of disasters, and the only way to improve outcome of the victims is learning lessons from past disasters. The need for research focused on data collection during times of disasters has been previously suggested.[4] This opinion article discusses the challenges health-care professionals face when collecting kidney-related data during large-scale disasters. Solutions to overcome these challenges are proposed with real-world examples, and insights from relevant literature and experience.

The data needed to analyze the kidney-related problems thoroughly fall into 2 separate categories. It is important to define these 2 categories but the challenges faced are very similar.

Prior Medical Records of Patients with Kidney Problems

It is important to have access to patients' prior medical records while evaluating the current kidney function. Some patients admitted with acute kidney problems related or unrelated to crush injuries may have prior chronic kidney disease, diabetes mellitus, or hypertension, among other comorbidities, which may have an impact on the management and outcome of the current kidney problem.

Prospective Data

Collecting prospective data at times of disasters may indeed be very challenging. However scientific value of prospectively collected data reflects more accurate and reliable information. Prospective data collection would mean, collecting and recording the information at the moment of the disasters. This may not be possible or ethical unless planned before a disaster has occurred anticipating all the difficulties that may be encountered during data collection.

Major Challenges in Collecting Kidney Data During Disasters

The major challenges in collecting data at the time of disasters can be divided into 2 broad categories:

(i) Data collection process itself
(ii) Data quality

CHALLENGES FOR THE DATA COLLECTION PROCESS ITSELF

Methodologies of Data Collection

Methodologies of data collection during and after disasters have previously been extensively discussed.[4,5] Use of routine electronic health information systems (REHIS) may be useful although suboptimal.[6] Collecting kidney data is a further challenge since it encompasses patients with acute and chronic kidney diseases and therefore needs a specialized and focused approach for each subgroup. Use of methods like hard copy data collection, REHIS, use of big data, and artificial intelligence may all be helpful.[7,8] Disaster preparedness should therefore also include strategies for data collection.

During disaster response, it can be difficult to coordinate data collection efforts across multiple health centers, especially when a pre-established template for data collection is not available. Standardized data collection templates are required to ensure uniform data recording and facilitate efficient data analysis and sharing across health-care facilities.

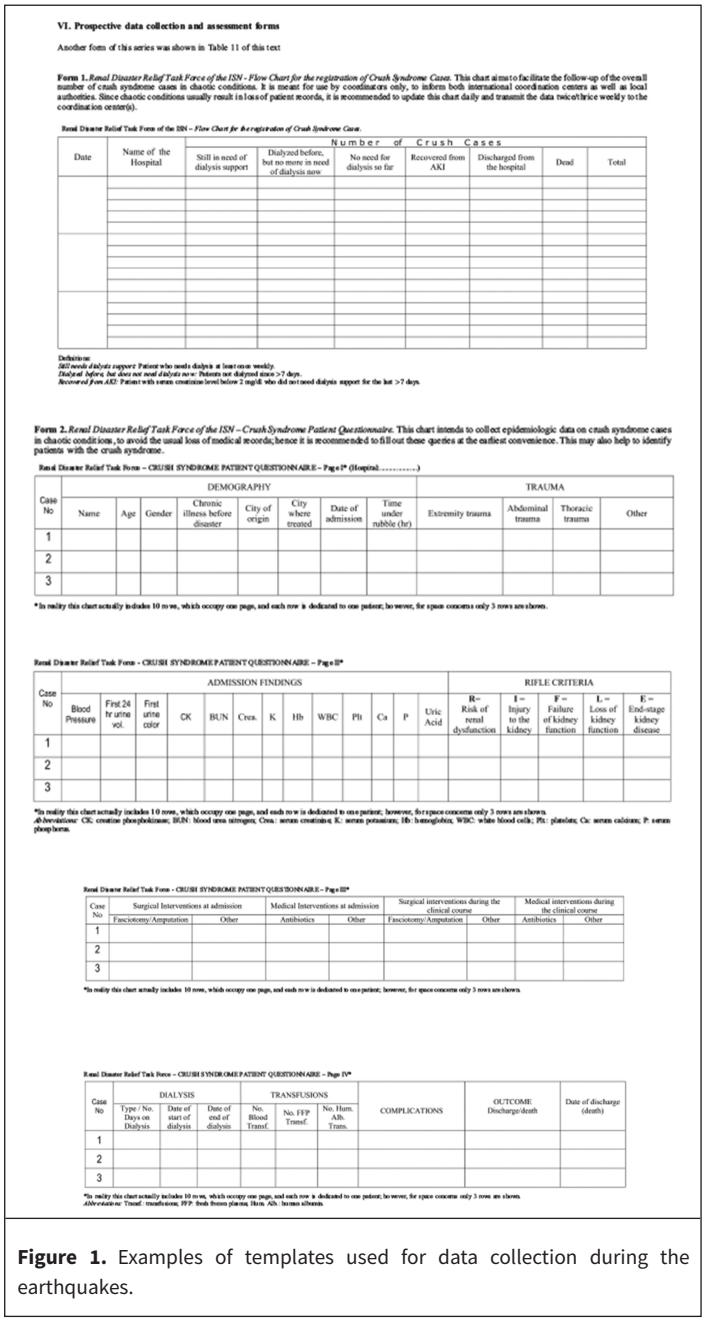
Studies conducted in disaster-affected areas also highlight the importance of preprepared data collection templates. For example, the lack of standardized templates during the 2015 Nepal earthquake hindered comprehensive data collection and analysis and made it difficult to accurately assess the impact of kidney complications.[9] On the other hand, in Marmara earthquake, patient data were collected on paper and then transferred to Microsoft Excel sheets. In the following years when other earthquakes occurred (2003, Bingöl; 2011, Van; 2018, İzmir) a template for data collection was prepared by the Renal Disaster Task Force of the Turkish Society of Nephrology, which was immediately disseminated following the occurrence of the latter earthquakes. Examples of templates are given in Figure 1. In the recent Southeastern Turkey earthquake, the latter template was used as a base to rapidly create a dataset as a PDF to be used as a bedside checklist and as a Google Forms document to be filled in from a mobile phone or computer. Therefore these templates can be available as hard copies, electronic templates, or online surveys. The pros of recording data in paper are that it is less costly and easy to use with a familiar format. It may also be quicker to use physically without time delays caused by slow loading times and unfamiliar interfaces. Spending precious time searching databases and scrolling through various screens to access prior records can be avoided. Paper templates can also be easily customized if needed. On the other hand, there are also some cons for collecting data on paper like the issue of storage, lack of backups, and limitations of security, especially in disaster settings. It may be time-consuming and prone to errors. As for electronic data collection, it is far more secure than paper records as they are not at risk during a catastrophic event. Electronic recording is always legible and may be more accurate. Currently, user-friendly formats are easier to form using various programs, and health-care professionals are far more familiar with the use of electronic recording compared to earlier.

Solution

To meet this challenge, disaster response planning should include the development and dissemination of standardized data collection templates for various medical specialties, including kidney care during a disaster-free period. Collaborative efforts involving health-care organizations and disaster response agencies can lead to the creation of comprehensive templates that cover the data points needed to assess kidney function and complications. These predefined templates should be simple, easy to fill in and the questions should cover only the key points. As stated earlier, they can be digital or on paper according to the circumstances and their availability. These templates can easily be disseminated through e-mailing. Ensuring the availability and accessibility of these templates can facilitate data collection and improve the overall quality of medical care during disasters.

Increased Burden on the Health-Care System and Operational Issues

Disasters put enormous strain on health systems as they cause a spike in casualties seeking emergency medical attention. The massive influx of patients can quickly overload hospitals and emergency departments, pushing the limits of health-care



VI. Prospective data collection and assessment forms

Another form of this series was shown in Table 11 of this text

Form 1. *Renal Disaster Relief Task Force of the ISN - Flow Chart for the registration of Crush Syndrome Cases.* This chart aims to facilitate the follow-up of the overall number of crush syndrome cases in chaotic conditions. It is meant for use by coordinators only, to inform both international coordination centers as well as local authorities. Since chaotic conditions usually result in loss of patient records, it is recommended to update this chart daily and transmit the data twice/thrice weekly to the coordination center(s).

Renal Disaster Relief Task Force of the ISN – *Flow Chart for the registration of Crush Syndrome Cases.*

Date	Name of the Hospital	Number of Crush Cases						
		Still in need of dialysis support	Dialyzed before, but no more in need of dialysis now	No need for dialysis so far	Recovered from AKI	Discharged from the hospital	Dead	Total

Definitions:
Still needs dialysis support: Patient who needs dialysis at least once weekly.
Dialyzed before, but does not need dialysis now: Patients not dialyzed since >7 days.
Recovered from AKI: Patient with serum creatinine level below 2 mg/dl who did not need dialysis support for the last >7 days.

Form 2. *Renal Disaster Relief Task Force of the ISN – Crush Syndrome Patient Questionnaire.* This chart intends to collect epidemiologic data on crush syndrome cases in chaotic conditions, to avoid the usual loss of medical records; hence it is recommended to fill out these queries at the earliest convenience. This may also help to identify patients with the crush syndrome.

Renal Disaster Relief Task Force – CRUSH SYNDROME PATIENT QUESTIONNAIRE – Page I* (Hospital:.....)

Case No	DEMOGRAPHY								TRAUMA			
	Name	Age	Gender	Chronic illness before disaster	City of origin	City where treated	Date of admission	Time under rubble (hr)	Extremity trauma	Abdominal trauma	Thoracic trauma	Other
1												
2												
3												

*In reality this chart actually includes 10 rows, which occupy one page, and each row is dedicated to one patient; however, for space concerns only 3 rows are shown.

Renal Disaster Relief Task Force - CRUSH SYNDROME PATIENT QUESTIONNAIRE – Page II*

Case No	ADMISSION FINDINGS													RIFLE CRITERIA				
	Blood Pressure	First 24 hr urine vol.	First urine color	CK	BUN	Crea.	K	Hb	WBC	Plt	Ca	P	Uric Acid	R= Risk of renal dysfunction	I = Injury to the kidney	F = Failure of kidney function	L = Loss of kidney function	E = End-stage kidney disease
1																		
2																		
3																		

*In reality this chart actually includes 10 rows, which occupy one page, and each row is dedicated to one patient; however, for space concerns only 3 rows are shown.
Abbreviations: CK: creatine phosphokinase; BUN: blood urea nitrogen; Crea.: serum creatinine; K: serum potassium; Hb: hemoglobin; WBC: white blood cells; Plt.: platelets; Ca: serum calcium; P: serum phosphorus.

Renal Disaster Relief Task Force - CRUSH SYNDROME PATIENT QUESTIONNAIRE – Page III*

Case No	Surgical Interventions at admission		Medical Interventions at admission		Surgical interventions during the clinical course		Medical interventions during the clinical course	
	Fasciotomy/Amputation	Other	Antibiotics	Other	Fasciotomy/Amputation	Other	Antibiotics	Other
1								
2								
3								

*In reality this chart actually includes 10 rows, which occupy one page, and each row is dedicated to one patient; however, for space concerns only 3 rows are shown.

Renal Disaster Relief Task Force – CRUSH SYNDROME PATIENT QUESTIONNAIRE – Page IV*

Case No	DIALYSIS			TRANSFUSIONS			COMPLICATIONS	OUTCOME Discharge/death	Date of discharge (death)
	Type / No. Days on Dialysis	Date of start of dialysis	Date of end of dialysis	No. Blood Transf.	No. FFP Transf.	No. Hum. Alb. Trans.			
1									
2									
3									

*In reality this chart actually includes 10 rows, which occupy one page, and each row is dedicated to one patient; however, for space concerns only 3 rows are shown.
Abbreviations: Transf.: transfusions; FFP: fresh frozen plasma; Hum. Alb.: human albumin.

Figure 1. Examples of templates used for data collection during the earthquakes.

resources. In these critical moments, health-care providers are faced with the daunting task of managing patients' triage while trying to make comprehensive assessments on treatment possibilities, status of health-care facilities, identities and overall health status of the victims as well as kidney function. Under these circumstances meticulous recording may not be possible or feasible. In the chaotic aftermath of natural disasters, health-care providers often prioritize emergency patient care over meticulous data collection and storage. Real-world examples from disaster events illustrate the challenges of data collection and storage. For example, the 2010 Haiti earthquake caused a rapid influx of casualties, leaving little time for comprehensive data recording.[10] Similarly, during the 2018 wildfires in California, health-care facilities faced difficulties in documenting patient data due to evacuation and emergency response priorities.[11]

Solution

Disaster response planning should emphasize the importance of real-time data recording. Streamlining data collection processes and using mobile devices for data entry purposes can help health-care providers quickly record key patient information. Asking for contributions from medical secretaries or medical students may be helpful as well. In addition, disaster response agencies should implement secure data storage systems that can withstand disasters and ensure that critical patient data are protected for future analysis and continuity of care.

Disruptions in Hospital Functionality and Power Supply

Power outages are a common consequence of natural disasters and exacerbate the difficulties faced by health-care facilities. Medical equipment, including devices used for kidney function testing and monitoring, often relies on electricity to function properly. Loss of power can disrupt these important systems, preventing timely collection and interpretation of kidney data. During the 2011 earthquake and tsunami of Great East Japan Earthquake, electricity, water, and gas were all cut off. Furthermore, many hospitals, including those with specialized kidney care units had to be closed.[12] Similarly, the 1999 Marmara earthquake in Turkey resulted in severely damaged health-care facilities and affected their capacity to provide adequate care to patients, including those with kidney complications.[13]

Solution

The lack of reliable power sources during disasters highlights the importance of having emergency plans and backup power systems. Hospitals and health-care facilities should prioritize securing alternative power sources to ensure continued operation of essential medical equipment and data management systems. Access to reliable power can significantly improve kidney data collection efficiency and contribute to more effective patient management during disasters. Additionally, the use of point-of-care testing (POCT) devices can be a valuable asset in disaster settings in the field and at the hospitals when urgent evaluation is needed for basic blood tests in a large number of patients. Point-of-care testing has especially been useful to stratify patients into those needing conservative management or dialysis, rapid diagnosis of electrolyte imbalances as well as complications like ketoacidosis during the Haiti and Chile earthquakes of early 2010.[14] Indeed, these devices are particularly useful for critical testing, including assessment of kidney function and allowing health-care providers to make timely and informed medical decisions. Furthermore, POCT eliminates the need to transport samples to central laboratories and hence partly decrease preanalytical errors. However, POCT use also has some drawbacks due to variable personnel training and control over preanalytical, analytical, and postanalytical variables, which can be better managed in a traditional laboratory

Table 1. Challenges and Solutions for Data Collection at Times of Disasters

Challenges	Solutions
Methodology for data collection	Dissemination of standardized data collection templates—digital or on paper
Increased burden on the health system and operational Issues	Disaster response planning
Disruptions in hospital functionality and power supply	Securing alternative power supply
Health-care workers' family responsibilities	Support and duty planning
Inadequate patient assessment and frequent referrals	Establishing protocols
Issues with patient identification and hospital records	Patient identification systems: photos/biometric systems
Damage to hospital information systems	Data backup and secure data storage
Ethical challenges	Developing preapproved ethics protocol templates
Inadequate preanalytical and analytical processes	Disaster response protocols Using POCT devices,
Improving reliable data collection	Motivation to participate in data collection

POCT, point-of-care testing.

setting. Technical drawbacks like operating within a limited temperature range seem to have been overcome over time. These devices are still very expensive for widespread use, and we believe that special funding for their use at times of emergency and disaster situations should be considered.

Health-Care Workers' Family Responsibilities

All health-care workers including the laboratory personnel, responding to disasters often face personal difficulties because of their family responsibilities. The need to care for their family and ensure their safety in emergencies can distract them from their professional duties, including data collection. During natural disasters, health-care workers may find themselves torn between their obligations at work and their desire to protect their loved ones. This emotional load can affect their professional functionality and impair their ability to focus on data collection tasks.[15]

Solution

To meet these challenges, disaster response plans should consider providing support services to the families of health-care workers working in emergency situations. Establishing designated family support centers and arranging regular communication channels can alleviate health-care professionals' concerns about the safety of their loved ones. Additionally, the inclusion of psychological support and stress management programs for health-care workers can contribute to their overall well-being and resilience during disaster response efforts. Furthermore, disaster response organizations should have contingency plans to ensure adequate staffing and staff rotation that allows health workers to take a break and attend to the needs of their families while responding effectively to the crisis. During the recent earthquake in Southeast Turkey, the immediate response action was to form a volunteer list of nephrologists and dialysis nurses/technicians by the relevant professional societies (Turkish Society of Nephrology and Turkish Society of Dialysis and Transplantation Nurses) and to coordinate the volunteers' transfer to the disaster area in collaboration with the health-care authorities. The work schedule was planned as a weekly rotation of volunteers to disaster areas, including breaks to avoid burnout.

Inadequate Patient Assessment and Frequent Referrals

Comprehensive medical examinations for all patients may be a difficult task to fulfill during disasters due to enormous caseloads health-care professionals have to face, limited resources, and urgent medical needs. This lack of adequate patient assessment can not only lead to underdiagnosis, including kidney complications, but also result in delayed or inappropriate treatments and inefficient, inadequate, and unreliable data collection. Literature from various catastrophic events highlights the impact of inadequate patient examinations on medical care. For example, during the 2010 Haiti earthquake, the large number of injured seeking medical attention strained health-care services and made it difficult to conduct comprehensive investigations.[10] Similarly, during the Nepal earthquake in 2015 the health-care needs exceeded the available health-care facilities, causing difficulties in providing comprehensive assessments for all patients.[9]

Solution

To meet this challenge, disaster response planning must include strategies for effectively prioritizing patients. Establishing protocols to identify and prioritize patients with potential kidney complications can ensure that these cases receive timely medical attention. Sending health-care teams specially trained in

kidney care to disaster areas can improve the accuracy and completeness of patient examinations, which will also be translated to efficient recording of the patient findings and laboratory data.

Issues with Patient Identification and Hospital Records

Following natural disasters, the loss of or damage to patient identification documents and hospital records can pose significant challenges for health-care providers. Disasters often cause chaos and disorder, making it difficult to access medical histories. Real-life examples from disaster-affected areas illustrate the impact of issues with patient identity and records. For example, after the earthquake that occurred in Nepal in 2015, health institutions faced difficulties in identifying and tracking patients due to the loss or damage of identity documents.[9] During the recent earthquake in southeast Turkey nephrologists working in the hospital also had limited access to patients' identities. This is especially an important issue for unconscious patients and the minors, not attended by their parents or any immediate family. The issue of correct identification of the patients also is very important for forensic reasons. Furthermore, the nephrologists as well as other health-care professionals could not obtain their patients' data because the digital data processing unit was not functional. Despite all efforts, even the handwritten paper notes of the patients on dialysis could not be found due to rapid evacuation of the hospital.

Solution

To mitigate the impact of problems with patient identification and records, disaster response plans should include measures to establish temporary patient identification systems. The application of photo identification and biometric systems can help patients accurately match their medical records, facilitating seamless data collection and patient management. Additionally, creating robust and secure data storage systems can help protect medical records from damage and increase their availability in an emergency.

Damage to Hospital Information Systems

The literature in disaster-affected areas highlights the impact of damage to hospital information systems on health-care delivery. For example, the 2011 earthquake in Japan severely disrupted hospital information systems, affecting access to patient records and medical history. Similarly, the Hurricane Sandy disaster in the United States wreaked havoc on hospital data centers, preventing timely retrieval of patient information [5]. Similar difficulties were encountered during the recent Southeastern Turkey earthquake.

Solution

During the recent Southeastern Turkey earthquake, the "e-pulse system," a type of cloud-based platform, successfully facilitated the retrospective collection of both historical and current patient data from the earthquake-affected region. This system provides access to patient's medical records from virtually any health-care facility. It has been implemented across all Turkish health-care facilities, allowing for recording of laboratory examinations, imaging, drug prescriptions, and medical conditions under each patient's name. This system enables medical information to be stored in an individual's dedicated "e-pulse" system. On the other hand, patients with chronic conditions, including chronic kidney disease, diabetes, and hypertension, and patients on kidney replacement therapies, including transplantation, should have a brief report of their medical conditions, the medications they are on, or any other relevant information with them at all times in case the information is needed in emergency and/or disaster conditions. It would be very useful for patients on hemodialysis or peritoneal dialysis to have their dialysis prescriptions with them at times of displacement due to disasters.[16] This medical record may be a hard copy and/or an electronically accessible version.

To mitigate the impact of damage to hospital information systems, disaster response planning should include robust data backup strategies. Cloud-based storage systems can serve as a secure and accessible means of storing critical patient data and ensure its availability even during infrastructure outages. Additionally, health-care facilities must prioritize securing data centers and implementing disaster recovery plans to restore their information systems as quickly as possible.

Ethical Challenges for Data Collection at Times of Disasters

Collecting data during disasters presents significant ethical challenges that must be carefully managed. It is crucial to prioritize patient privacy, maintain confidentiality, and ensure robust data security in such chaotic settings. The standard protocols for safeguarding patient information in clinical settings become even more critical in these crisis. Furthermore, if the collected data are intended for research, scientific publication, or quality assurance reports in the future, ethical considerations must be taken into account right from the outset. In the midst of a disaster, preparing all the necessary documents for an ethics committee application may not be an easy task. For instance, during the recent Southeast Turkey earthquake, obtaining ethics committee approval required a fast-track approach. However, this process can be better planned in advance.

Solution

One potential solution is to develop preapproved ethics protocol templates, endorsed by both clinical and research ethics committees as has been recommended for pandemic and outbreak scenarios.[17] These templates can be modified with contextual details for an expedited review and approval under specific disaster situations. Furthermore, it is essential to inform populations residing in disaster-prone regions, like Turkey, about the importance of data collection during disasters. In these extreme circumstances, obtaining informed consent from individuals is often unrealistic. Therefore, privacy and security of data storage systems pose significant challenges that must be factored into disaster preparedness planning. Decisions regarding who

can access the data and for what purposes, whether patient names will be included or if data will be deidentified, and considerations about the storage of samples should all be carefully addressed. The European Renal Association COVID-19 Database (commonly known as ERACODA) Project can be an example for data collection at times of disasters.[18]

DATA QUALITY

Inadequate Preanalytical and Analytical processes

In disaster scenarios, rapid and accurate assessment of patients' medical conditions becomes crucial, and laboratory tests play a crucial role in achieving this goal. Time-sensitive laboratory tests such as electrocardiograms, blood glucose measurements, and blood gas analyzes provide rapid results that help health-care providers make critical medical decisions quickly.[19] However, the challenges of disaster response can lead to inadequate preanalytical and analytical processes during laboratory testing, potentially compromising the accuracy of test results, including those related to kidney function. The literature on laboratory practice during disaster responses sheds light on the challenges health-care providers face in adhering to standard preanalytical and analytical procedure protocols. In the urgency of disaster environments, time constraints and overwhelming caseloads can lead to deviations from established protocols for sample collection and handling.[20,21] The need for rapid medical decision-making can inadvertently lead to shortcuts in laboratory procedures, potentially leading to errors in test results. For example, inadequate specimen collection techniques can affect the accuracy of kidney function tests, such as serum creatinine levels, which are crucial for assessing kidney health. The implications of erroneous laboratory results can be particularly important in the context of kidney care during disasters. For example, during the Southeastern Turkey earthquake, creatine kinase level was reported as 7U/L in some of the severely traumatized patients (personal communication). Likewise, potassium, lactate dehydrogenase, and various enzyme levels can be reported in abnormally different levels.

Solution

Health-care providers involved in disaster response efforts should receive training in maintaining best practices even under challenging conditions. Ensuring proper sample collection, labeling, and handling techniques can help minimize potential errors and increase the reliability of laboratory results. By incorporating robust disaster response protocols, training on appropriate laboratory practices, and using POCT devices, health-care providers can increase the accuracy and efficiency of laboratory testing, thereby optimizing kidney care and patient outcomes in disaster settings.

Improving Reliable Data Collection

Medical data collection during times of disasters relies mainly on health-care workers. Physicians and nurses may be too overwhelmed to fulfill this task. Furthermore, they may feel uneasy to be concentrating on data collection and/or planning or being part of a scientific research project at the very moment of a disaster situation with some ethical considerations. Ethical issues for research in disasters has been beautifully addressed before.[22]

Solution

The importance of scientific contribution in building up reliable information in disaster setting to serve for a better preparedness in future disasters must be conveyed to the participants in data collection. Auxiliary health-care workers and medical students may also be encouraged to help with data collection. The most important aspects are to keep the data collection as simple and straightforward as possible, making sure that data collection does not put the affected population at risk and respecting individual privacy.

CONCLUSION

Some of the drawbacks in writing about collecting kidney data during times of disasters are that the literature on this issue are scarce, and there are no established methodologies for this task; therefore, data may be missing despite all efforts. We believe that the points stated earlier and data collection methodologies as well as possible challenges and solutions must be integrated into disaster preparedness training. Composing a core group on behalf of the national/international societies may be a good strategy. Establishing local kidney disaster task forces within the national societies may also be useful in this aspect.

Despite all efforts, natural or man-made disasters do occur. Preparedness is the key to mitigate the effects of disasters on the communities. Collecting, recording, storing medical data at times of disasters, although very challenging, is of utmost importance to take steps for preparedness based on scientific evidence.

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