

Know Your Patient Rights and Responsibilities

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In the past 10 years, the media has been awash with stories of different patient rights violations and medical negligence and malpractice cases. These stories have been profiled by different human rights advocates, legal experts, and patient advocates. One of the stories captured is a case against the Nakaseke district local government filed by the Center for Health, Human Rights, and Development (CEHURD) and David Mugerwa

On 5th May 2011, Mugerwa David took his wife Nanteza Irene to the Nakaseke District Hospital to deliver their baby. The mother was admitted at 1.35 pm, upon examination, Miss Nanteza was told she could expect a normal birth. The waters of the mother had broken already, and she was in advanced stages of Labor (cervix dilation was 8cm). In fact, given how the labor was progressing, the mother was expected to give birth by 5 pm the same day. However, at 4 pm, the mother's condition changed and was diagnosed by the midwife to have obstructed labor. The nurse notified the husband of the change in condition and the requirement of an emergency c-section to save the life of the mother and baby since the health of the baby was deteriorating fast. The doctor on duty was called at 4.30 pm and informed of the need for an emergency c-section, but he was not in hospital. He had been last seen in hospital at 11 am. The doctor arrived 4.5 hours later at about 9 pm. Nanteza and her baby died before the doctor could perform the emergency C-section. The cause of death was excessive bleeding from a ruptured uterus. Despite the hospital administrator's awareness of Nanteza's condition and the doctor's absence before her death, he did not make any effort to transfer her to another hospital.

Some of these stories have been captured in media as legal proceedings in court and sometimes as cases investigated and resolved by health professional councils. A study done by Gakumba, Katongole, and Bikaitwoha in 2015, shows an increasing trend of medical litigation cases. This study indicates that of the 10 Kampala hospitals surveyed 2 had received notification of intention to sue, 3 had cases in court and 5 had cases being investigated by Uganda Medical and Dental Practitioner Council. Although this trend partly shows success in the empowerment of patients to know their rights, it also portrays, the sad reality of continuous violation of patient's rights in health facilities and the failure of healthcare facilities, their management, and individual providers to respect patient rights and to deliver safe care

Health facilities and individual health professionals fail to respect patient rights because they don't fully know them, nor do they understand how to apply them in practice. If they know them, other systemic failures hinder their ability to fulfill them. Similarly, patients don't know their rights. As stated in the last segment, for patients who know their rights, many do not know to whom to report their concerns. If patients report their concerns, health facilities do not adequately act on their complaints, mainly due to a poor patient safety culture at the facility level that does not encourage learning from errors. This usually leaves the patient with no option but to seek justice from the courts of law.

Nanteza's case is one of those that were investigated by courts of law. In her case, Nakaseke's local government was held vicariously liable for the doctor's breach of duty by being absent from duty without permission from or notification of his supervisor. Nakaseke district local government was held liable for failing to ensure Nanteza got the emergency care she needed and for failing to ensure that the doctor employed to provide such care was present on the day in question. This absence led to a failure to provide the deceased with "the timely, immediate, and emergency obstetric care that she needed to overcome the 'obstructed labor.

Nanteza's right to health care was violated. In Uganda, everyone in need of health is entitled to impartial access to treatment under regulations, conditions, and arrangements in the health care system. At the hospital level of care, Nakaseke Hospital should have been able to conduct an

emergency C-section. However, it was not done because the doctor on call was absent, and the hospital management should have referred Nanteza to a place where the emergency C-section could be done within 2 hours of recognizing that they could not offer the needed emergency services. She and her family should have been told why and where they were referring her for further care. A referral note should be written, and she should have been accompanied by a healthcare professional during the referral. In the referral facility, she would be entitled to receive medical care unconditionally without having to pay any deposits or fees before medical care.

However, all this was not done, because neither the patient nor her family knew this right to health care, nor did Nakaseke Hospital refer Nanteza to get the care she urgently needed, and the hospital could not provide it. The consequence of their inaction led to her death. Death by a ruptured uterus is a terrible way for a woman to die.

In this segment, we continue to talk about patient rights so that you are empowered to make informed decisions about your health and demand for quality and safe care. This can go a long way in reducing avoidable harm to patients.

A right to receive care without discrimination: No health facility or health provider should discriminate between patients on grounds of disease, religion, tribe, clan, political affiliation, disability, race, sex, age, social status, ethnicity, nationality, country of birth, sexual orientation, or other such grounds.

A right to be referred for a Second Opinion. Every person has the right to be referred for or seek an alternate opinion with or without request or when indicated.

Refusal of Treatment

Patients have the right to refuse treatment after receiving information to make an informed decision. Such refusal can be offered verbally, in writing, or by conduct. This decision can be made by the patient or his/ her authorized representative. The patient should be explained to the consequences of their refusal of treatment and should take responsibility for these consequences. The provider is only obligated to respect the patient's decision to refuse treatment provided that such a decision does not endanger the health of others. Instances when a patient's refusal of treatment can endanger the health of others include if the patient's illness or disease is a public health concern. Diseases of public health concern are diseases that can spread very quickly for example cholera, Ebola, Marburg, Human rabies, Smallpox, Yellow fever, Typhoid, bloody diarrhea(shigella), measles, acute viral hepatitis (sudden onset of yellowing of eyes), plague and meningococcal meningitis.

The provider also has the right to go against the patient's choice to refuse treatment, when protecting an unborn child, minor or disadvantaged person or when a court has ordered.

The right to participate in decision-making: Every citizen has the right to participate or be represented in the development of health policies and systems through legally recognized institutions. This right calls for individuals to get involved in making decisions about their health. Individuals and communities can get involved by forwarding health concerns to their community health workers, the facility in charge, and members of health unit management committees. They can attend public consultations on health and environmental policies and procedures, join organized community action groups, and participate in petitions and discussions. Patients can also forward their concerns to the Uganda Alliance of Patient Organizations (UAPO). This is an independent patient-driven national advocacy organization with members from across different disease areas. UAPO advocates for an efficient health system built on a strong foundation of patient-centered care and meaningful patient participation in health research and policy development.

Confidentiality

Patients have a right to privacy during their treatment. All Information concerning the patient's health, including treatment information may only be disclosed with informed consent. Facility

management should ensure that the health service providers do not disclose any patient matters brought to their knowledge during the provision of health services.

However, a Health facility or health worker may pass on medical information to a third person in the following circumstances. If the disclosure is for the patient's treatment by another health worker when required by law or court order when the disclosure is vital for the protection of the health of others or the public, and the need for disclosure overrides the interest in the information's nondisclosure. Disclosure of patient information may also be allowed if it is for publication in a medical journal or for research or teaching purposes. However, all details identifying the patient should be removed.

Custody of Medical Records

The patient is the legal owner of his/her medical records. The health facility is the custodian of the medical records and will ensure that confidentiality is adhered to. The health facility as a custodian for medical achieves is mandated to keep records about the general health condition of patients for 25 years after a file is created or 3 years after the death of an individual. Similarly for obstetric conditions, the medical record should also be kept for 25 years after the birth of a live baby or a stillbirth. Whereas for psychiatric conditions, patient records are kept for the lifetime of the patient and 3 years after the patient's death. However, after the stipulated timelines, health facilities are not obligated to destroy the records. For research purposes, clinicians may ask for indefinite retention of records.

A right to a healthy and safe environment: An environment that ensures physical, mental, and social well-being, including adequate water supply, sanitation, and waste disposal facilities, free from pollution, ecological degradation, and infection.

Every patient has a right to be attended to by an identified service provider and know their name and cadre or position. By the service standards, all healthcare staff in the facility should wear identification badges. Health workers are obliged to introduce themselves to their patients at first encounter.

Right to safety and security; Every patient has the right to safety and security to the extent that the practices and medical equipment in health facilities do not harm. This right to safety applies to a patient's physical, sexual, and mental safety.

Right to receive Visitors: Patients are entitled to request, receive, and refuse visitors at any time according to the guidelines provided by the health facility management. However, patients in psychiatric facilities, intensive care units, and isolation units may not receive visitors or can only receive visitors under the supervision of health care professionals. When clinically appropriate, family members should participate in the emotional, spiritual, and physical care of patients, participate in ward rounds, and meet with members of the health care team.

Right to Choose Medicine and Care.

A patient has the right to choose where they purchase medicines and care, not necessarily in the health facility where they are being treated.

Right to Transparency in charged fee rates.

The patient has a right to know the charged fee rates for medicines and medical care and receive an itemized bill.

Rights of Discharge or Receive Dead Body

Patients have a right to shorten the length of their stay and a right to be discharged. If a patient dies, caretakers have a right to take the dead body and may not be detained at the health facility because of procedural reasons or pay disputes.

In as much observance of patients protects them from abuse, harm and discriminations, patients have roles and responsibilities to ensure the best outcomes from their health care. Patients should provide health care providers with complete and accurate information about their conditions to enable providers arrive at right diagnosis. They should adhere to prescribed medicine and all procedures meant to improve their health; this includes adopting healthy behaviour to prevent disease. They should respect rights of other patients. They should refrain from verbal abuse or physical violence against health service providers or other providers.

Patient- provider relationship is unique, based on trust, respect, open communication mutual understanding. Do your part as a patient and let providers do they part too.

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