

Why is it important to know your rights as a patient?

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A successful patient-provider interaction relies on an honest exchange of information. In this exchange, the patient trusts the provider to understand their health issues and to determine the best course of action. However, for this interaction to yield the best results, both patients and providers need to know their rights and obligations to one another.

Recently a friend shared an experience she had 3 years ago when she went to hospital for an operation. Before the procedure, they removed a large amount of blood for testing. She was never told what was being tested, nor did they tell her about the findings from the tests even though she inquired to know about the findings from the tests. The operation was done in the evening. Six hours later at about midnight. She was in so much pain. Pain medication given in the theatre had worn off. However, upon looking for a health provider to raise her concern, none was found on the ward. Her caretaker tried to reach any provider but could not find any on the ward. It took her over an hour to find a nurse in the hospital who came and administered the pain medication. All this time the patient was convulsing in pain. She kept wondering what the surgical notes said about her pain management. She asked to see the instructions for her post-operative care, but a copy of her medical file was never availed. She felt so helpless in the face of providers who she felt were holding all the cards. Although she wanted to raise her concerns, she did not know who to talk to in the facility about her experience.

This is one of the many untold experiences patients face daily. It is an example of a violation of patients' rights. In this instance, five rights of the patient were violated; a right to informed consent: a right to medical information: a right to continuity of care: a right to proper care, and a right to feedback and redress. The government of Uganda is committed to ensuring that all people have access to high-quality care services. The Patient's Rights and Responsibilities Charter of 2019 and Comprehensive Health Service Standards Manual of 2021 are of the ways the government is ensuring that care offered to patients meets the needs of patients and is safe and effective. The care must be offered in a timely and efficient way, and without discrimination. The comprehensive service standards of 2021 are revisions of 2016 standards. Whereas the Patients' Rights and Responsibilities Charter of 2019 is a revision of the Charter of 2009.

The charter details the rights and responsibilities of patients, whereas the comprehensive health service standards provide a framework for assessing if care is given by the right health care provider, doing the right thing, in the right way, to the right person, at the right time. These service standards help guide efforts to improve the quality of care to meet the expectations of consumers. Unfortunately, many patients and providers alike are not aware of the patient's rights. Hence such violations persist during health care provision.

There is numerous anecdotal evidence that points to violations of the rights of patients. However, most of these experiences go unreported because patients are not empowered to speak, and do not know their rights, and proper procedures for logging complaints. The patients think health providers are doing them a favor by treating them and hence fear being discriminated against if they raise concerns about any rights violation. A study done by Harriet Rachel Kagoya and colleagues in 2013 amongst patients and providers in Mulago Hospital showed that of 211 patients interviewed 172 had never heard of the patient charter. Of 39 who had heard about the charter, more than half of them indicated that they did not fully know their rights. Of 98 providers interviewed 68 had never heard of a patient's charter. The study also reports that

of 77 patients who reported to have faced a challenge regarding their rights while seeking care, 60 of them never attempted to demand their rights.

The patient rights and responsibilities charter details 20 rights for patients. The service standards also emphasize that every person should receive dignified care, their rights respected, protected, and always fulfilled during care and without discrimination. Health providers should understand the patients charter and service standards and how to apply them in practice. All people should be told about the patients' charter as it pertains to their right to care in an appropriate local language during health care visits. In this first segment we unpack 5 rights of patients.

A right to Proper health care

A patient is entitled to appropriate health care. Delivered professionally while adhering to service standards, by qualified health care practitioners and in a way that is sensitive to patients' cultural and religious preferences and based on clinical need. In the instance above, the patient should have received proper post-operative care, which should have included proper and adequate monitoring, timely identification, and intervention to any challenges arising during post-operative period.

Continuity of Care.

A Patient should not be abandoned by a health care provider or a health facility that initially took responsibility for their health care unless the patient chooses otherwise. Facilities should have mechanisms for ensuring continuity of care, including plans of care to be written down and explained to patients and families in a language that they can understand. In the experience given above, the patient was not given information about her post-operative care plan. The patient and her caretaker should have been told about what was being monitored, how, and at which interval. The patient and caregivers should have been informed about their roles in post-operative care.

Given the right information about the care plans; patients, families, and caregivers are vigilant observers of a patient's condition and can easily alert healthcare professionals when a new need arises. Providers should be readily available to monitor and respond to any issues that arise to ensure timely intervention.

Informed consent

Every patient has a right to be given adequate and accurate information about the nature of one's illness, diagnostic procedures, and proposed treatment for one to make a decision that affects any one of these elements. This information should be communicated to the patient at the earliest opportunity and in a language, they understand so that they can make a free, informed, and independent choice. Informed consent may be given verbally or in writing or demonstrated by patients' behavior and should be witnessed. This right also gives the clinician permission to withhold medical information from the patient concerning his/her condition if he/she strongly feels that by giving this information, it is likely to cause severe harm to the patient's mental or physical health.

In the patient's experience narrated above, the patient was not given any information about the blood tests which were done, nor was she told about the findings from the tests. She was never allowed to choose whether the tests should be done because no one explained to her the reason for doing the tests.

Sharing accurate information about illness, diagnostic procedures, and proposed treatment helps patients to be contributors to their care, make decisions about their care, have realistic expectations of benefits and possible harm of the treatments, and increase the likelihood of treatment adherence. It also improves communication between patients and providers allowing personalized and effective care hence improving patient experience, quality of care, and patient satisfaction.

Right to Medical Information.

A patient has a right to obtain health information concerning himself/herself, including a copy of his/her medical records from the health service provider or the medical facility. Patients should have access to their medical records during treatments and should be assisted by health professionals to understand the information in the file.

Right to Feedback and Redress

Every health facility should have an established mechanism for patient feedback and a designated person or a committee to be responsible for the observance of patient rights. Such a person or committee has to ensure patients' rights are observed. They should receive, investigate, and process patient's complaints. They should educate and instruct all medical and administrative staff in the facility in all matters regarding the patient's rights and ensure that a mechanism for feedback is established.

Patients and carers should be made aware of the designated person or committee responsible for feedback and redress and mechanisms for logging patient complaints and feedback. Health workers should encourage clients to actively discuss any problem with their health and treatment during the visit. Patients' feedback should be processed and acted upon. This is because patients travel through the entire care system and hence are more likely than health workers to have a holistic view of the care process. They are the only ones who have a full insight into the outcome of their care. Consequently, their insights into how care can be made better and safer are invaluable.

Observance of patients' rights protects patients against abuse, discrimination, harm and helps providers to practice ethically, and ensures patient safety. Knowing your rights as a patient helps you take responsibility for your health, hold providers, facilities, and government accountable to the services provided, demand for quality services, and offer feedback to strengthen overall health service delivery.

In our next segment, we shall talk about other rights of patients.



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