



Will Health Rights Solve Malawi's Health Problems?

We are living in a world where the mode of thinking is being increasingly influenced by Western ideology. The discourse about personal rights is one of the consequences of Western philosophy. Malawi, a south-eastern African country, has produced a Charter of Patients and Health Workers' Rights and Responsibilities. Implementation of this document is expected to contribute to improving the delivery and accessibility of high quality health care for all the people in Malawi without any discrimination. The Charter is not yet a legally binding document as is the case in other countries, but rather an aspiration of the Malawi people to embrace a human-rights approach to health care delivery.

The history of the Charter of Rights for Patients dates back to the early 1990s, when the Medical Council of Malawi, the regulatory body for medical doctors, laboratory scientists and technicians, and other paramedical professions decided to develop a code on human rights of some sort. The idea was little explored and many years passed without much progress. This may have been due to the fact that the general political environment at the time was not as conducive to such human-rights discourse as the country was under a one-party autocratic rule until 1994.

From 1994 however, Malawi has experienced an increased appreciation of human rights among its citizens. This started with the introduction of multi-political party system, the change of government from the Malawi Congress Party (1964-1994) to the United Democratic Front (UDF) (1994 to 2004). Within the 10-year period under the UDF, the country has witnessed the establishment of the offices of the Ombudsman, Law Commission, Malawi Human Rights Commission, and a proliferation of non-governmental organiza-

tions and civil society groups aimed at the advancement of political and socio-economic rights.

Despite the fact that general community awareness, promotion, and protection of political rights has improved, similar gains are yet to be made in socio-economic rights as applicable to the health sector.

In 2000, the Malawi Health Equity Network (MHEN), a grouping of non-governmental agencies, regulatory bodies, individual activists, health professionals, researchers, and academics started a campaign to institutionalize the Patients and Health Workers' Charter of Rights and Responsibilities. It was thought that one way of improving the quality of care in the Malawi health system was to use health rights as a tool for such a goal. This work has now been adopted by the Department of Community Health at Malawi's only medical school. Program activities involve: school essay competitions on health rights, public lectures, use of various forms of mass media in promoting awareness in health rights, training of health professionals and key community stakeholders, and development, research, and distribution of relevant information and communication materials, such as posters and brochures. In this essay, I will present the literature review on health rights as a part of human rights, and health globally and in Malawi, the program's research findings on the promotion of health rights, and the challenges faced and opportunities for improvement identified. The paper draws on the experience of the Health Rights and Governance Project (HRGP) work within the Malawi College of Medicine. The aim of the HRGP is to promote availability and accessibility of high quality health care for all people in Malawi and to achieve this through education and training, research, and advocacy.

Literature Review

Section 13 (c) of the Constitution of the Republic of Malawi states that the "States shall actively promote the welfare and development of the people of Malawi by progressively adopting and implementing policies and legislation aimed at achieving ... health" and "To promote adequate health care, commensurate with the health needs of Malawian society and international standards of health care" (1). This section identifies the obligation of the State to ensure that there is adequate health care for all (without discrimination) in Malawi.

Although it may not be specifically mentioned that health care delivery is based on the respect of human rights, this is implied through teaching and observance of ethical principles of respect for autonomy, justice, beneficence, and non-maleficence. Respect for autonomy is implemented through the promotion of privacy, confidentiality, inclusiveness in decision making by involving the patient, informed consent for procedures, and respecting patient wishes. Justice, loosely defined as fairness, may be exemplified through fair distribution of health resources by person, disease category, geographical location in a country, and respect for patients' appointments and sometimes the "first come first served" rule. In emergency situations, the patient with greatest need may be attended to first, as this is normally construed as adequately fair. The "first do no harm" indirectly promotes beneficence and non-maleficence and challenges futile interventions.

The United Nations adopted the Universal Declaration of Human Rights (UDHR) in 1948 (2). However, UN declaration is not as enforceable as some other conventions, such the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social, and Cultural Rights (ICESCR) (3,4). The UDHR, ICESCR and the International Covenant on Civil and Political Rights constitute the internationally recognized International Bill of Rights. Other international documents that affirm the right to health are the UN Charter, UDHR, ICESCR, the Constitution of the World Health Organization (WHO), and the 1978 Declaration of Alma-Ata International Conference on Primary Health Care (5,6).

The present review is based on literature review, interviews with key stakeholders in the health care sector including patients, patient groups, and health professionals, public comments solicited through newspaper notices, and discussions after open public lectures. The purpose of the review was to determine the acceptance of the Patients' Charter of Rights and Responsibilities, and identify opportunities and challenges of the Charter's implementation. Data were obtained and analyzed using qualitative methods.

The Charter of Patients' Rights and Responsibilities has two parts regarding patient rights and responsibilities presented in Tables 1 and 2 (7). Health workers also have rights and responsibilities that are spelt out, but have not been shown in this paper.

Opportunities

The HRGP initiative aims at increasing the awareness of patients' rights and obligations within a general socio-political environment where the rights discourse is vibrant. Efforts to highlight rights within the health care sector can therefore draw lessons and complement the general political rights.

Our work has also been facilitated by the support of the Ministry of Health (Ministry in further text) and the National Assembly. At the start of the project, both the Ministry and the Health and Population Committee of the National Assembly were briefed and were supportive of the initiative. We believe our work would have been hampered if these important national entities were opposed to the promotion of health rights.

Challenges

Despite the fact that there is increased appreciation of political rights in Malawi, there is skepticism among both health professionals and community members that either party would be interested in fulfilling the obligations to ensure the rights of the other. Health professionals, for instance, have expressed concerns that patients might understand that one of their health rights is the right to boss over the health professionals. In an environment where health professionals seemed to have enjoyed a sense of paternalism, a suggestion as to qualify patients as equal partners threatens that state of affairs. Aveyard (8) reported a study of self reports by nurse practitioners, where

Table 1. Patients rights in the Malawi Health Care system*

1. Right to access to health care	<ul style="list-style-type: none"> - Every individual shall have access to health care and treatment according to his/her health need. - Every patient has the right to be cared for by a competent health worker regardless of age, gender, ethnicity, religion, economic status, and without any form of discrimination. - Every patient has the right to access medicines, vaccines, and other pharmaceutical supplies of acceptable standards in terms of quality, efficacy, and safety as determined by the Pharmacy, Medicines, and Poisons Board. - Every individual has the right to prompt emergency treatment from the nearest public or private health facility.
2. Right to choice and second opinion	<ul style="list-style-type: none"> - Every patient has the right to choose a health facility from which to obtain care in line with the prescribed health delivery system. - Every patient has the right to a second opinion at any time.
3. Right to adequate information and health education	<ul style="list-style-type: none"> - Every patient has the right to know the identity and professional status of the person providing the care. - Every patient has the right to have adequate information regarding all aspects of care, including the right to adequate information on diagnosis and tests performed; medicines prescribed; reason for prescription, the dose, duration of taking medicine, side effects, and safety. - Every patient shall be informed of the reason for any referral to another health facility or health care provider. - Every patient shall be given information about self-care, drug administration, and preventive measures which may be necessary. - Every individual has the right to seek and obtain information regarding preventive, curative, and rehabilitative medicine. - Every patient has the right to know his or her prognosis.
4. Right to informed consent/refusal of treatment	<ul style="list-style-type: none"> - Every patient or guardian shall provide informed consent before any surgical procedure is carried out, but so however that such consent may be waived in case of emergency or in certain psychiatric cases.
5. Right to participation/representation	<ul style="list-style-type: none"> - Every patient has the right to participate in decision-making affecting his/her health through: <ul style="list-style-type: none"> - discussion with the health professionals and personnel involved in direct health care; - consumer and community representation in planning and evaluating the system of health services, the types and qualities of service, and the conditions under which health services are or were delivered.
6. Right to respect and dignity	<ul style="list-style-type: none"> - Every patient shall be treated with kindness, consideration, respect, and dignity with no regard to age, gender, ethnicity, religion, economic status, and without any form of discrimination.
7. Right to a guardian	<ul style="list-style-type: none"> - Every child admitted to a hospital shall, wherever possible, have the right to the company of a parent or guardian.
8. Right to privacy and confidentiality	<ul style="list-style-type: none"> - Every individual has the right to have the details regarding his/her diagnosis, treatment, prognosis, and other aspects of his/her care kept confidential. There may be situations when there may be need to disclose the patient's information, for instance: <ul style="list-style-type: none"> - if authorized by the patient; - public health reason; - if patient is unable to consent and it is the patient's own interest to disclose such information; - if the information is required for due legal process; - if medical records are required for continued care by another health care provider.
9. Right to a safe environment	<ul style="list-style-type: none"> - Every individual has the right to a safe and clean health care facility.
10. Right to complain about health services	<ul style="list-style-type: none"> - Everyone has the right to complain about health care services and to have such complaints investigated and to receive a full response on such investigation.

*Source: Ministry of Health, 2003; ref. 7.

the patient's decision to consent or refuse treatment was not respected, and the refusal of care by patients was especially not given due regards.

In the Malawian context, some people considered the change from autocratic rule to a democratic government as a license "to behave as one wishes," without regard to responsibilities. Both health professionals and patients have expressed this concern. However, the charter of rights as presented above also has a section on the responsibilities of patients.

The paternalistic approach to health care delivery is not only preferred by health professionals, as patients do many times accept and even request for it. We believe this may be due to the socialization that patients have been exposed

to. We also believe if there are concerted efforts to ensure that this approach is changed, patients will also adapt and similarly appreciate a much more participatory health care system.

In the training of health professionals, we encourage them to treat patients as "our guests." We also borrow from the language of Dr Anne Merriman, the founder of Hospice Africa (9), that as health professionals, "we have just met the patients and therefore we are strangers to them. However, patients have lived with their body for many years and, therefore, know their body better than we may be able to." This is to emphasize that the patient must be treated with respect, their dignity must be respected and we should not attempt to prevent them from telling us their body's story, as they are

Table 2. Patients responsibilities in the Malawi Health Care system*

Every patient shall ensure that he/she knows and understands what the patients' rights are and shall exercise the rights reasonably and responsibly.

Every patient shall conduct himself/herself so as not to interfere with the rights or well being of other patients and health care providers.

Every patient shall accept all the consequences of the patient's own informed decisions.

Every patient has the responsibility to ensure or maintain his/her own health and that of society by refraining from:

- consumption of unhealthy food and water;
- consumption of alcohol, drugs, substances of abuse and tobacco;
- irresponsible sexual activity and other life styles that are hazardous to health;
- degradation of the environment.

Every patient has the responsibility to provide health care providers with relevant and accurate information for diagnostic treatment, rehabilitation, or counseling purposes.

Every patient must know his/her local health care providers and what services they offer.

Where applicable, every patient is responsible for settling his/her bills at times as requested by the health providers.

Every patient shall comply with the prescribed treatment and keep appointments and shall inform the health professional in good time if unable to do so.

Every patient has the responsibility to take care of his/her health records in his/her possession.

*Source: Ministry of Health 2003; ref. 7.

better placed to inform anyone about their own body, despite the fact that they may not be competent to interpret what is going on within them.

Participatory Decision-making

Decision making in clinical practice has been described in terms of an activity-passivity construct (9): thus ranging from a situation where the individual makes treatment decisions, to a joint decision made by the patient and the health professional, and finally to the situation in which the health professional makes the treatment decision on behalf of, and without input from the patient. While we agree with the main aspects of the concept, we would like to suggest an extension of this construct as may be operational in our environment. The activity-passivity construct could be further explained as follows: a) a situation where the patient makes treatment decision alone; b) where there is joint decision-making between the health professional and the patient; c) where there is joint decision making among the health professional, the patient and significant others; d) where significant others make treatment decision without the involvement of the patient but with involvement of the health professional; e) where significant others make treatment decisions without involvement of either the patient or the health professional; and f) where the health professional makes decision without involvement of neither patient nor significant others.

Whereas the lack of inclusiveness in decision-making by health professionals can occur due to lack of respect for dignity of the patient, ignorance that participatory decision making supports good clinical care, or the fact that patients may abrogate their responsibility or right to be in-

cluded in decisions concerning their treatment. On the part of the health professional, inclusiveness in decision-making requires time, space, and skills which they may not possess. In our situation, where the health professional to patient ratio is low, sparing adequate time to consider patients preferences competes with the need to attend to many patients. Whereas the right to be consulted and participate may be respected for one patient, the right to access care by another patient may be infringed.

One of the respondents in the stakeholder interviews reported that since most of services in the public health system were free, there was an attitude among health professional of "take or leave it." When we gave participants several options as to who should make treatment decisions, the profile presented in Table 3 was obtained.

Table 3. Preferences for treatment decision making in a survey of the health practices in Malawi

Decision maker	No. (%)
Patient with guidance from health professional	14 (25.1)
Patient alone	13 (23.0)
Patient/and guardian	10 (18.0)
Health professional alone	10 (18.0)
Health professional in consultation with patient/guardian	4 (7.3)
All persons involved in the care of the patient	4 (7.3)

Limited Human Resources

The health sector in Malawi, like in many other countries in southern Africa, is experiencing increased work load, among other reasons, because of AIDS and the out-migration of nurses to overseas developed nations (10). Overall resources (material, human resources and financial) are in short supply. Health professionals ask us

how patients are going to enjoy the best possible health care under the prevailing situation of severe resources limitation. Patients also do not have high expectations of the health sector as they appreciate the resource limitations that the country is experiencing. Other resources limitations identified in the interviews with stakeholders were: shortage of medicines and other pharmaceuticals, overcrowding of admission wards, and poor transport facilities for patients. Rural areas were identified as being severely limited in essentially all resources.

In order to illustrate the human resources situation in Malawi, we present the distribution of doctors, clinical officers and nurses, and bed occupancy at the four tertiary centers (Table 4), as well as the human resources situation in all five districts of the Northern Region of Malawi (Table 5). Clinical officers and medical assistants are trained for 3 years and 2 years respectively to provide clinical consultations. As the number of doctors in Malawi is just about 200, clinical officers and medical assistants fill an important niche in the provision of clinical care.

Table 4. Bed occupancy and health professionals in the four referral hospitals in Malawi, July 2002-June 2003*

Hospital	Bed capacity	Bed occupancy (%)	Clinicians	Nurses
Mzuzu	262	74	46	177
Kamuzu	623	93	157	476
Zomba	332	106	50	200
Queen Elizabeth	872	61	73	544

*According to ref. 10. Clinicians include both doctors and clinical officers.

Limited Financial Resources

According to the Ministry of Health (2003), the per capita drug and recurrent expenditure (not including expenditure on personnel emoluments) ranged from about MWK 50 (Malawian Kwacha, MWK100 = US\$0.089) for Blantyre and Lilongwe (two main cities in Malawi) to MWK 317 per capita annually (11).

Functioning water supplies in the health facilities in Malawi in 2003 ranged from 13% in Karonga to 100% in Salima (mean 59%), only

65% of the health facilities had functioning water supplies (range 13% to 100% per district) and 58% of the health facilities had functioning medical waste disposal facilities (11). The right to a safe health facility is unlikely to be respected in such situations where water is not available and medical wastes indiscriminately disposed; the right to prompt care may be limited by the lack of a functioning communication system for patient referrals. Whereas the reversal of this trend will require the efforts of health professionals, it is clear that other government departments, such as Water Department and Treasury, have a part to play in ensuring the observance of human rights. Health professionals on their own are unlikely to promote the respect for human rights effectively as some of the necessary interventions are beyond their mandate to change.

In March 2005, Kamuzu Central Hospital had 188 nurses, a decrease from 476 in 2003 (12). Now the question that we are faced with is whether the patient has the right to choose among more health professionals or to seek a second opinion.

Right to Privacy

The respect of the right to privacy is another issue which health professionals have difficulties ensuring. The majority of admission wards in Malawi do not have separate rooms to accommodate small number of patients. A typical admission ward is a large space, accommodating 30 to 60 patients at a time. Privacy is achieved through the use of fabric screens and having sensitive discussions with patients in a separate room. But as has been described by Malcom (13), whereas fabric curtains can provide visual privacy, they are unable to effectively provide auditory privacy. Further, in our setting, it is not unusual to have patients sharing a bed and some sleeping under another patient's bed.

The other option, where patients are called to a separate room for the discussion of sensitive issues, is an alternative to fabric curtains or

Table 5. Nurses and doctors in the five Northern region districts of Malawi*

District (estimated population)	Doctors in post	Clinical officers	Medical assistants	Nurses	Population per nurse	Population per doctor
Chitipa (143,468)	0	6	8	31	4,628	-
Karonga (77,265)	2	11	15	85	909	110,016
Nkhata Bay (196,245)	1	11	12	49	4,005	196,269
Rumphi (162,168)	2	8	17	58	2,796	81,079
Mzimba (635,666)	2	13	23	118	5,387	317,856

*Source: Ministry of Health, 2003, ref. 7.

no curtain at all. However, the shortfall of this approach is that as some of the patients stay in the wards for long periods, and some of them have gone through the same process, they soon identify the purpose of calling a patient to a private conversation, ie a serious illness which, in our setting, is likely to be AIDS. Patients who have received bad news from a private discussion also have little opportunity for private reflection in private rooms, but are discharged once more to the public ward to face the "gaze" and sometimes inquiry from fellow patients.

We are not advocating a change in the current arrangement of the architectural layout of the wards, although for future construction, this should be considered, but rather call for health professionals' higher sensitivity to privacy. The respect of privacy is not just about ward layout but about other things, such as not discussing patient information in the corridors, standing closer to the head of the bed while talking to the patient and speaking in a lower tone of voice.

In the tertiary hospitals where the teaching of nursing and medical students during wards rounds occurs, maintaining privacy is also problematic if teaching and discussions occur right at the ward. Teaching and ward staff, as well as students, need to recognize and anticipate situations where a breach of a patient's privacy is likely to occur and aim at providing alternative ways of achieving the desired educational goal. For instance, in some cases patients can be examined outside the wards, and their history and examinations discussed afterwards. One respondent said: "Many patients get mistreated, and asked about their illness in the presence of other patients, which makes them lie about their diseases; no one complains because they think that is how things should be."

Limited Health Information

We have identified that health professionals and patients may not have the requisite information to enable them to make informed decisions and participate adequately in shared treatment decision-making. On the part of health professionals, we believe one contributing factor is that continued professional development (CPD) or continued medical education (CME) is not a requirement for re-registration or practice license renewal (14). As long as an individual is able to pay

the set amount of money to the regulatory bodies, one's license is guaranteed to be renewed. This, in our opinion, has resulted in health workers who may not be up to date with health information and may be uncomfortable dealing with patient who may be more knowledgeable in certain aspects than the professionals.

The majority of Malawians are also illiterate. The provision of health information through leaflets using the written word is not useful, unless much of the information is given in pictures. Radio and posters are among the commonest ways of disseminating information. However, these methods have the limitation of usually presenting rather shallow messages, and retention and permanence of radio messages for continued reference is problematic. This therefore means that many of our patients do not get enough information to be able to make treatment decisions on complex medical conditions.

If patients are to enjoy their rights, they ought to have a degree of self efficacy and expect that others will respect them. In our interviews with stakeholders, 53 out of 55 (96%) of the respondents said that patients do not know their rights. It was also reported that patients may not be interested to know about their rights and seemed to be "prepared to be shouted at."

One respondent said: "It is a two way problem because patients fail to ask for what they need because they don't know what to ask for and even the behavior of some nurses and doctors may be caused by their lack of knowledge of patients rights."

Religious Rights

It was also reported in the key stakeholder interviews that there was need for health professionals to accept that patients may choose alternative treatments based on religious conviction. An example to illustrate this point was that the choice of Jehovah's Witness believers who may refuse life saving blood transfusion, should be respected. Unlike in Malawi, where there is no legal guidance in case of a parent who refuses life saving treatment on behalf of a child, South Africa's High Court has ruled that it is unacceptable for a parent to decide on withholding of life-saving treatment on behalf of a child (15). We are unaware of any situation where health professionals in Malawi have sought the intervention of the courts to overrule parent refusal to treatment.

Many times however, health professionals would respect parent preferences. We are of the opinion that in such situations where health professionals are unsure, the recourse of courts should be sought. The work of health professionals is made even more difficult because the health associations for nurses and medical practitioners are dormant. We have previously reported on such a situation and lack of input of the relevant associations to issues of importance in the health sector in Malawi such as health professionals' welfare (16).

Role of Traditional Healers

The traditional healing system is the recognized health system in Malawi. Tuberculosis and sexually transmitted infections patients have been reported to be delayed from accessing effective care by the traditional healing system (17-19). The 2003 Health Management Information Bulletin reported that only 41% of pregnant women were delivered by trained health personnel, and 21% by traditional birth attendants (11). If health rights are to be respected, health services providers, other than the formal health system, need to be involved in the education and training and advocacy campaigns.

Conclusion

I believe the quality of health care services in Malawi can be improved through the promotion and respect of human rights. Patients, the Ministry of Health and health professionals are the key to such a goal but are not the only critical ingredients. Traditional healers, other government departments (Treasury, Water, Communications), courts, civil society, and researchers are all crucial if the goal is to be achieved. The health professionals' association should mobilize for health rights, and the regulatory bodies (Medical Council of Malawi and Nurses and Midwives Council of Malawi) should seriously consider the introduction of mandatory continued professional development if the quality of health care is to improve in Malawi.

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